NUFFIELD
COUNCIL ON
BIOETHICS

Genome editing and human reproduction public survey
December 2017

Index

Analysis by question

Background

1. As a part of the evidence gathering activities for the Council's inquiry into the ethical issues raised by genome editing and human reproduction, an online public survey, based around three potential human reproductive genome editing scenarios was conducted. The survey was intended to complement other consultation exercises conducted as part of the Council's inquiry by gathering a wide range of views from members of the public for use in the deliberations of the working party.

2. The survey was designed in-house and launched using the Survey Monkey online survey platform. It comprised 16 substantive questions; 15 substantive multiple choice questions and one substantive free-text question. A free-text comment box was presented alongside each multiple choice question for respondents to expand on their response.

3. The survey was open for eight weeks between 15 May and 14 July 2017. It was promoted using standard Council channels comprising social media, organisation mailing lists, working party and Council member contacts and other networks. External organisations, such as the Medical Research Council were asked to promote the survey; the Academy of Medical Sciences, Association of Medical Research Charities, Genetic Alliance UK, the PHG Foundation, the Parliamentary Office for Science and Technology (POST) the Royal Society and a number of other organisations tweeted about the survey when it went live.

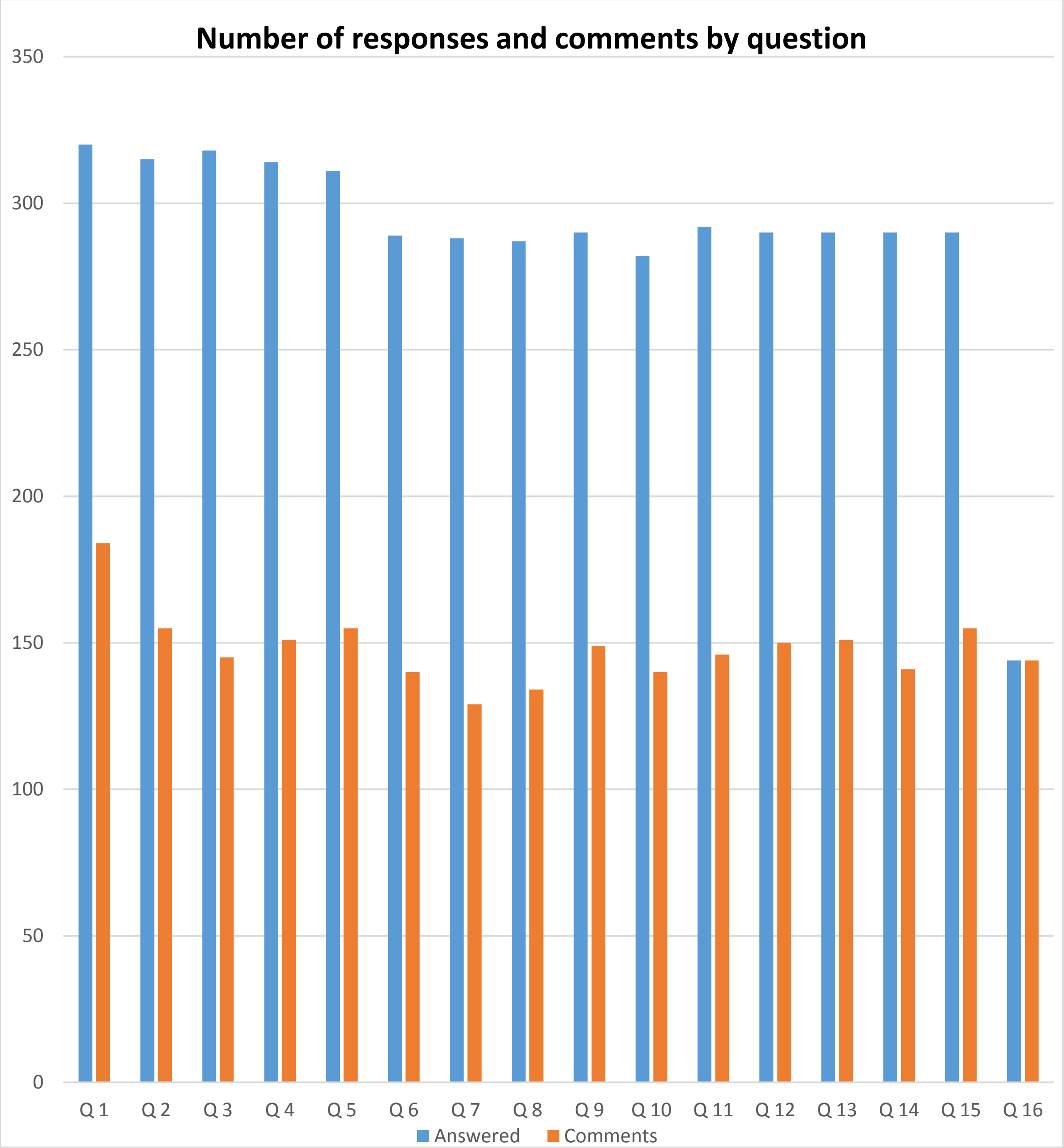
4. The deadline for responses to the survey was initially 1 July but this was extended on 30 June by two weeks until 14 July after an interim review of survey respondent profile identified a lower survey response rate from younger people and from people with lower educational achievement. In an effort to encourage more responses from these groups Council Communications colleagues purchased a 'boost' on the Council's Facebook page which targeted promotion of the survey at younger people. Communications colleagues also approached the UK Youth Parliament to encourage responses from its members. In spite of these efforts, the survey received relatively small number of responses from these groups (see pp.4 and 7).

5. 320 responses to the public survey were received in total.

6. This document summarises the survey responses. It contains graphical representations of responses to each of the multiple choice questions, and an analysis of comments made by survey respondents organised according to which multiple choice answer they gave to each of the 15 substantive multiple choice questions. Quoted comments are attributed to respondents by reference to seven demographic variables requested from those who completed the survey: nationality; gender; parental status; age; level of educational attainment; whether respondent had a family member with a genetic condition; and whether the respondent had had a genetic test (though all comments used as illustrative quotes in the summary were selected from a catalogue stripped of all demographic information). The summary aims to identify some of the themes of responses to each question and to describe a range of views represented in the survey responses. It does not comprehensively list all the points made in the questionnaire responses or identify the frequency with which the points highlighted were made.

Response and respondent profile

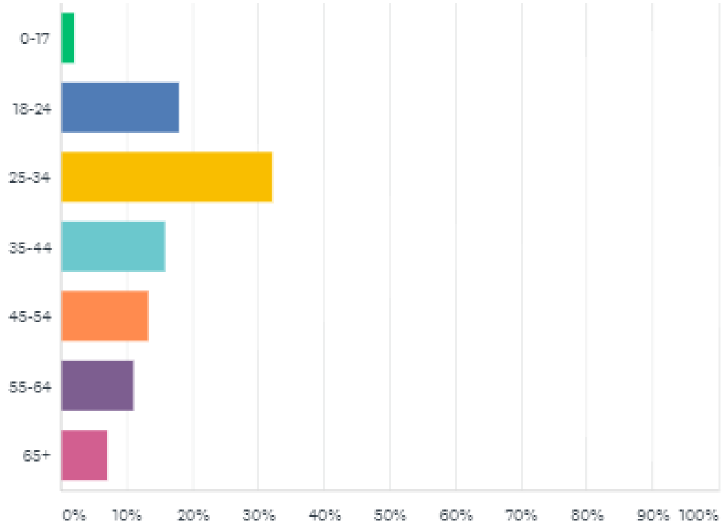
1. The survey received 320 responses in total. Not all respondents answered each question. Each question received more multiple choice responses than it generated explanatory comments (see graph below). The substantive multiple choice question that had the highest response was question one which received 320 responses. The substantive multiple question that had the lowest response was question ten which had 282 responses. The substantive multiple choice question that generated the highest number of explanatory comments was question one which generated 184 explanatory comments. The substantive multiple choice question that generated the fewest explanatory comments was question seven which generated 129 comments.

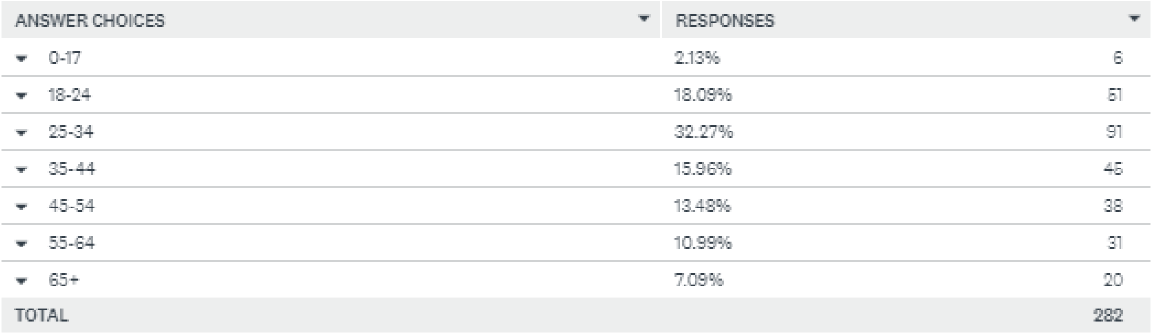


2. Survey respondents were asked eight non-substantive questions about their membership of different demographic groups. The survey contained six non-substantive multiple choice questions about: age, gender, parental status, whether the respondent or a family member had been personally affected by a genetic condition, whether the respondent had ever had a genetic test, and the respondent's educational achievement. Respondents were also asked two free-text questions about their nationality and place of residence. Responses to these questions are represented graphically below.

How old are you?

Answered: 282 Skipped: 38

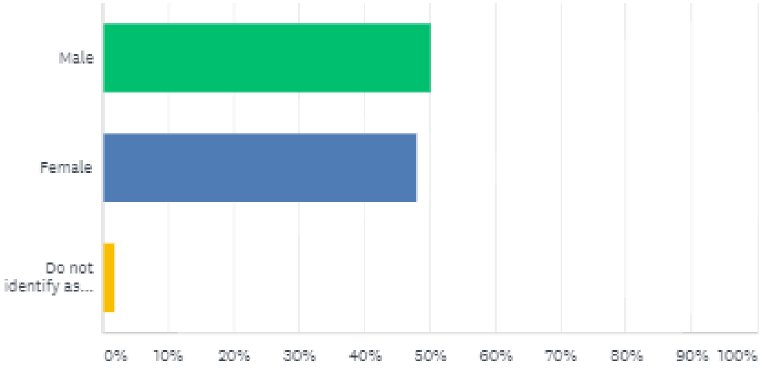




ANSWER CHOICES	RESPONSES	
0-17	2.13%	6
18-24	18.09%	51
25-34	32.27%	91
35-44	15.96%	45
45-54	13.48%	38
55-64	10.99%	31
65+	7.09%	20
TOTAL		282

What is your gender?

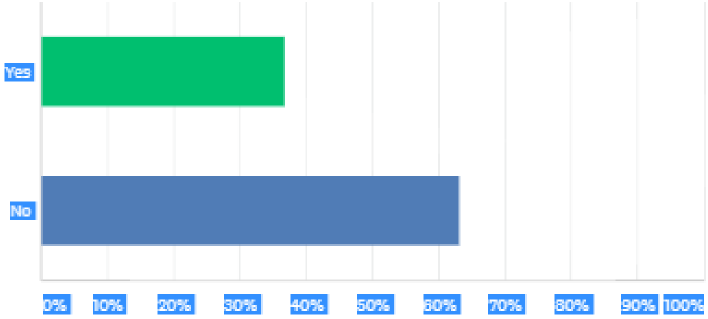
Answered: 281 Skipped: 39



ANSWER CHOICES	RESPONSES	
Male	50.18%	141
Female	48.04%	135
Do not identify as male or female	1.78%	5
TOTAL		281

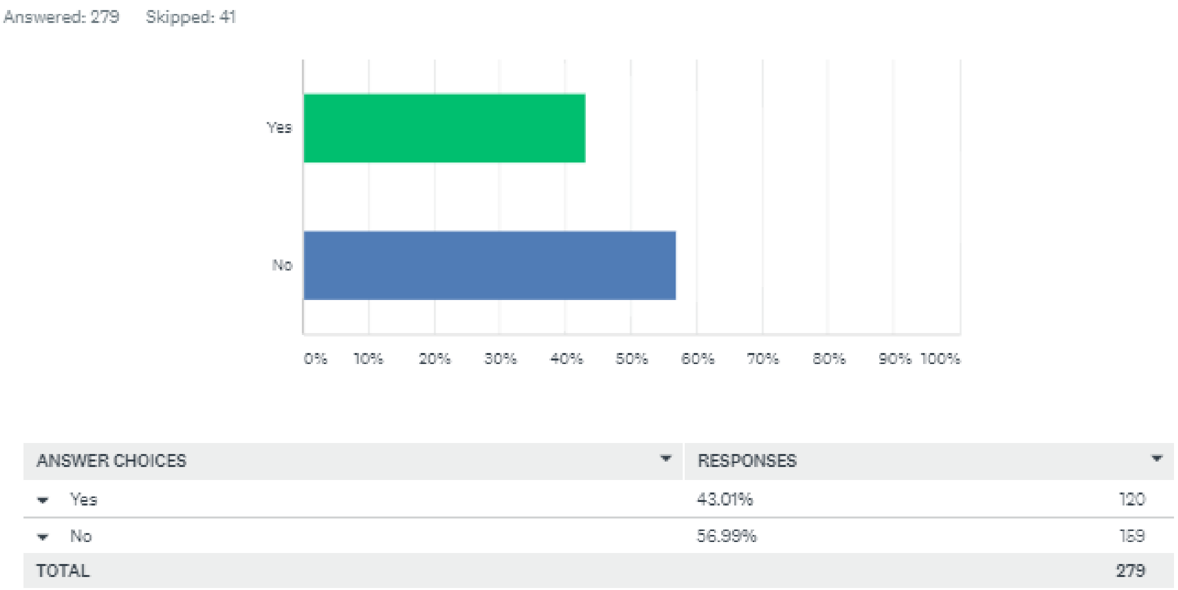
Are you a parent?

Answered: 280 Skipped: 40



ANSWER CHOICES	RESPONSES	
Yes	36.79%	103
No	63.21%	177
TOTAL		280

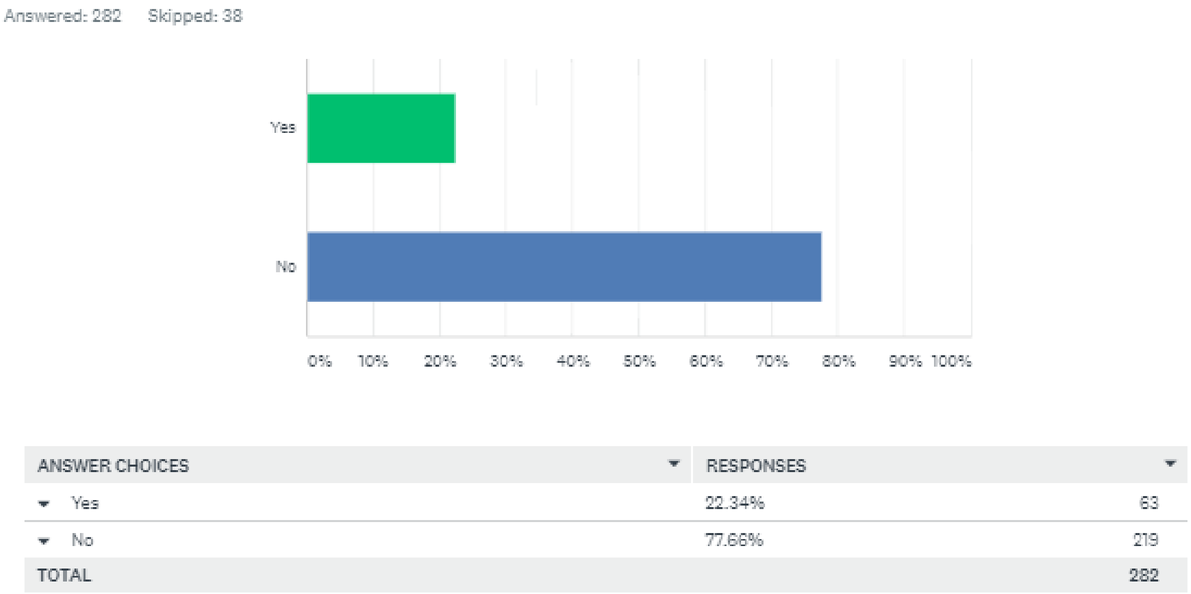
Have you or any member of your family been personally affected by a genetic condition, or a condition with a genetic component (such as familial breast cancer), that has involved consultation with a health professional?



Answered: 279 Skipped: 41

ANSWER CHOICES	RESPONSES	
Yes	43.01%	120
No	56.99%	159
TOTAL		279

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)?

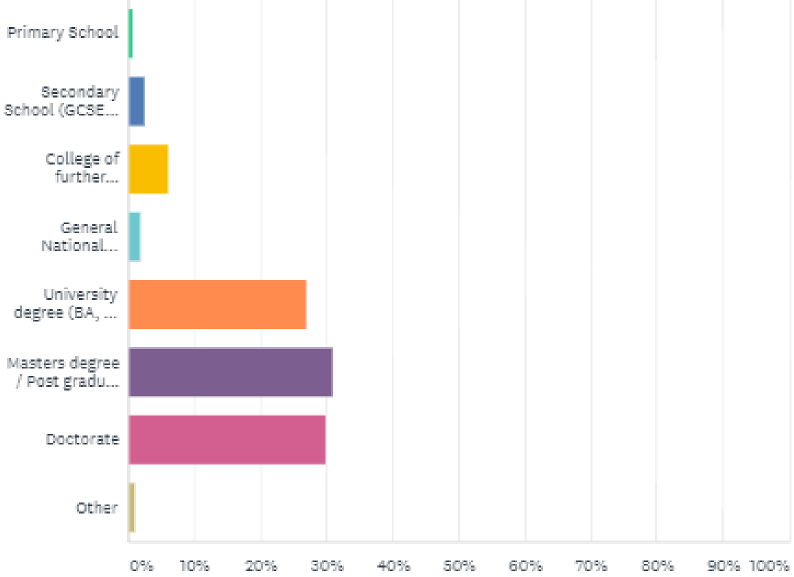


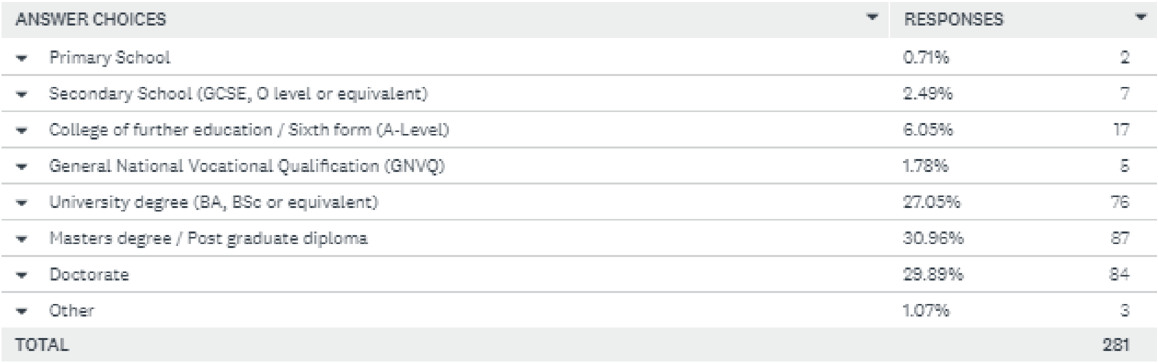
Answered: 282 Skipped: 38

ANSWER CHOICES	RESPONSES	
Yes	22.34%	63
No	77.66%	219
TOTAL		282

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

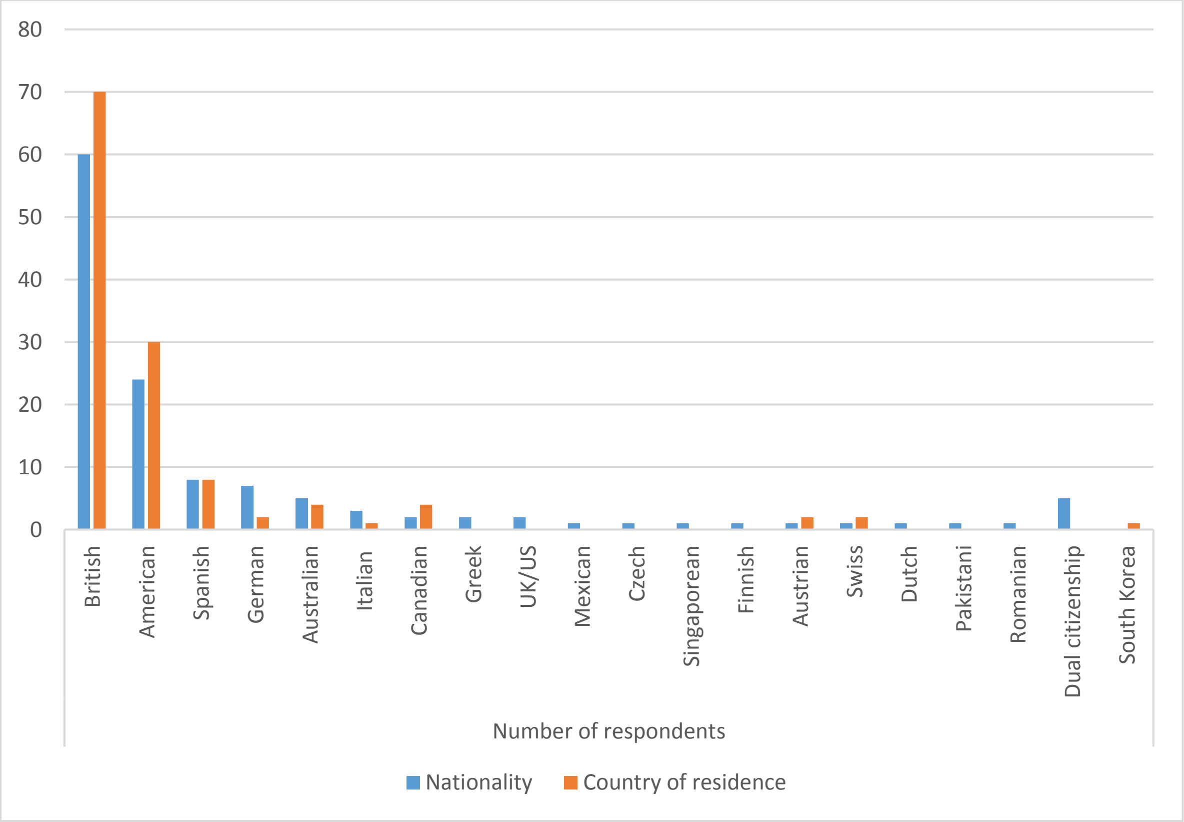
Answered: 281 Skipped: 39





ANSWER CHOICES	RESPONSES	
Primary School	0.71%	2
Secondary School (GCSE, O level or equivalent)	2.49%	7
College of further education / Sixth form (A-Level)	6.05%	17
General National Vocational Qualification (GNVQ)	1.78%	5
University degree (BA, BSc or equivalent)	27.05%	76
Masters degree / Post graduate diploma	30.96%	87
Doctorate	29.89%	84
Other	1.07%	3
TOTAL		281

What is your nationality? What is your country of residence?



Summary of themes across all questions

Some ideas emerged as themes of respondent comments across a number of the survey questions. A short overview of these is given below.

1. *Safety, risk and uncertainty*

Safety, risk and uncertainty about the long term effects of genome editing in human reproduction were raised by respondents as important considerations in nearly every question in the survey. Sometimes respondents clarified that their support of the use of genome editing was conditioned on its safety.

> *If the procedure is deemed safe, I see no reason for it not to be made available to them.* (Q1)
> *French male non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *I can't see any legal reasons why it shouldn't be allowed. Safety is the primary concern.* (Q3)
> *British male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Respondents also cited concerns about safety as reasons for which they opposed the use of genome editing.

> *Potential safety concerns regarding altering embryos.* (Q4)
> *British female non-parent, 25-34, doctorate, no genetic condition in family, not genetically tested*

> *Again, back to safety. I do not believe this procedure is safe enough to say that everyone should be required to use it, because I do not accept the original value proposition.* (Q10)
> *American male non-parent, 25-34, postgraduate, not genetically tested, genetic condition in family*

Uncertainty about short and long-term safety of altering or removing genes was raised by respondents in reply to a number of survey questions, alongside scepticism about the confidence with which human beings would ever be able to view editing the genomes of embryos as safe.

> *Again, "never" is a good approximation for when we will know enough to have this discussion.* (Q5)
> *British/American male non-parent, 65+, postgraduate, not genetically tested*

> *We have no idea what secondary effects may come from this e.g. inability to concentrate etc.* (Q12)
> *British male non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

> *There doesn't seem to be a way to properly test the risks of this.* (Q14)
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

A related issue raised in this context was the need for further research and evidence on genome editing and human reproduction.

> *I think that more long-term studies are required before I am willing to accept this type of intervention. Particularly, altering genetics of a population in such a quick manner can have unintended consequences that reach far beyond the one species being treated.* (Q1)

> *American male non-parent, 25-34, graduate, genetic condition in family, not genetically tested*
>
> *More research should be done to examine whether such a genetic abnormality may also contain certain genetic benefits before the procedure is rolled out.* (Q2)
> British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested
>
> *From current knowledge, it appears the genome editing technique in question - CRISPR - has lots of issues - while it may correct a gene, it may leave lots of unintended, off-target changes that cannot be easily scanned for. Perhaps it is best to do more research on human embryos first to really assess the technique before it is used in the clinic.* (Q16)
> *Singaporean male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

2. Reproductive choice, freedom and rights

A strong theme in many of respondents' comments concerned the significance of personal freedom and reproductive choice. Respondents in reply to a number of survey questions said that the couples in the scenarios described should be allowed to make their own personal decisions about whether to use genome editing procedures or not.

> *Same as before: basic freedom, consenting and informed adults, no third parties harmed. (Q*6)
> *American male non-parent, 45-54, Doctorate, genetic condition in family, not genetically tested*
>
> *This is down to personal choice and if the couple feel that this is their only option then it should be down to them to make it, having taken advice from the relevant medical professionals and done proper research into why it is illegal in the UK but not in the other country.* (Q8)
> *British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

Sometimes these ideas were expressed in terms of reproductive rights.

> *Their right to choose to have children through a straightforward genetic 'repair', just the same as any other couple, who may also require medical interventions to have children.* (Q1)
> *British female non-parent, 55-64, graduate, genetic condition in family, genetically tested*
>
> *This is their right if they decide to do so. I hope their UK doctors would support them with questions and information they need before they go for the treatment.* (Q8)
> *British female non-parent, 55-64, graduate, genetic condition in family, genetically tested*

Sometimes respondents mentioned individual privacy in the context of choice also.

> *The couple's decision is private. Having intelligent children may have downsides, but it is within the rights of parents to choose this.* (Q13)
> *American male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*
>
> *Procreative freedom and right to privacy* (Q11)
> *female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

3. *Societal issues including access, fairness, inequality and use of public resources*

Respondents raised issues relating to inequality, fair access, and other kinds of societal issues in reply to a number of the survey questions. Concerns about the principle fair access were raised by respondents, objecting in some cases to the prospect of wealthy individuals being able to access benefits unavailable to those with less means.

> *I strongly disagree with people's wealth, class, status etc determining their genetic advantages.* (Q9)
> *British male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*
>
> *Unless the procedure were to be universally available through public funding, it would be hugely unfair to allow those well off enough to afford it a huge advantage that is not available to others.* (Q11)
> *British female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

Some were also worried about social stratification or other societal effects.

> *How will this affect reproduction rate of rich vs. poorer people? This needs to be further examined.* (Q1)
> *German male non-parent, 35-44, graduate, no genetic condition in family, not genetically tested*
>
> *Neither are acceptable because both mark the advent of a new techno-eugenics that would set us on the road towards division of the human community into genetic castes - the "gene-rich" and the "gene-poor" - and eventually to human speciation.* (Q4)
> *American male non-parent, 65+, doctorate, genetic condition in family, not genetically tested*
>
> *Once again, this must be available to all to make it ethical, otherwise only those who can afford it will have access to it and slowly but surely the wealthy elite will transform their children into a genetically superior "master race".* (Q13)
> *British male non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested*

Related questions about public service provision, availability on the NHS in the UK and resource allocation were also raised in response to more than one question, with differing views about whether fairness required that heritable genome editing be made available, or whether it would be unfair, insofar as it would not constitute a good use of public resources.

> *If the procedure were to be available as an NHS treatment what would the cost be and how would access to this treatment be allocated?* (Q1)
> *British female parent, 55-64, postgraduate, genetic condition in family, genetically tested*
>
> *The NHS has the right to consider value for money in the procedures it funds. We must accept that as part of a public healthcare system. Chris and Dara's situation is unfortunate but the money spent on the procedure could be best spent elsewhere.* (Q9)
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*
>
> *If all couples in the area were offered the same choice then it may be acceptable.* (Q11)

British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested

4. Welfare of the child

Comments about the effects of heritable genome editing procedures on the children born from edited cells were raised in response to a number of questions, with references to the child's welfare, quality of life, happiness, health and other features being cited as important considerations in responses to a number of questions.

> *The child's welfare outweighs the parents' personal or religious beliefs.* (Q10)
> *British male non-parent, 35-44, postgraduate, not genetically tested, no genetic condition in family*
>
> *I think it would all depend on the quality of life the child would have with this condition. If the person was going to be severely disabled and live basically as a vegetable, it may be more considered versus a child that will have to undergo some procedures and regularly visit a doctor but live a relatively 'normal' life (even if reduced).* (Q6)
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*
>
> *Decreased mortality/better quality of life due to removal of genetic diseases is good.* (Q15)
> *No demographic data provided*

Those adopting opposing stances towards heritable genome editing sometimes appealed to the fact that they thought the described procedure would not necessarily benefit the child.

> *There is no guarantee that having an exceptionally intelligent child will give that child a better quality of life.* (Q13)
> *British male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*
>
> *Intelligence doesn't equal happiness. I'd probably endorse gene editing to ensure happiness?!* (Q13)
> *Welsh female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

5. Availability of alternative options

A theme relating to the availability of alternative solutions to problems or issues described in the survey's described scenarios was visible across a number of the survey questions. In one context, this could broadly be described as concern about endeavours to address social or man-made challenges with tools of genetic modification, such as to increase drought resistance or intelligence, both of which some respondents felt should be addressed with environmental and educational policies instead.

> *This wouldn't be preventing an inherited illness or life limiting condition. For me the money would be better spent on improving the education system for the benefit of a whole generation of children rather than benefitting one individual.* (Q13)
> *British female parent, 55-64, graduate, genetic condition in family, genetically tested*

> *We have a responsibility collectively to make a world that is fit for future generations and our resources would be better directed to taking action to allocate environmental degradation.* (Q14)
> *British female parent, 55-64, postgraduate, genetic condition in family, genetically tested*

> *Again, fix social problems (pollution, dependence on fossil fuels, neoliberal economics, excessive individualism, competition) not people. Otherwise we don't deserve to survive.* (Q14)
> *British male non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested.*

The availability of alternative means of becoming parents was also seen by some as relevant. Some respondents suggested that the availability of gamete donation, preimplantation genetic diagnosis (PGD) or adoption carried implications for the appropriateness or acceptability of genome editing in human reproduction.

> *They can adopt.* (Q1)
> *Australian female non-parent, 45-54, Postgraduate, genetic condition in family, genetically tested*

> *This is not a neutral question -- if the reader responds no, they are essentially denying this couple a healthy child. This couple would have the option of PGD, sperm donation or adoption -- there is absolutely no reason to edit their future child's genes. See #1.* (Q6)
> *American female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *They should be encouraged to adopt instead of breed.* (Q10)
> *Demographic data not provided*

6. Pressure on prospective parents use genome editing technique

Another theme to emerge was the possibility of the availability of genome editing procedures creating an expectation that people make use of it. Some expressed concern about this and took the view social disapproval for not using genome editing techniques would be a bad thing.

> *A couple deciding on the grounds of personal beliefs and values not to undertake the procedure should be shown due respect and not be penalised for holding to their beliefs.* (Q10)
> *British male parent, 65+, postgraduate, not genetically tested, genetic condition in family*

> *I don't think people should be expected to use the procedure, but I also don't think the justification for this is freedom of choice. It seems reasonable that couples like this should have access to prenatal testing and termination if they are not in a position to raise a disabled child, and no pressure should be put on them either way.*
> *Australian female non-parent, 45-54, postgraduate, not genetically tested, no genetic condition in family*

Others suggested that such expectations would be warranted and expressed the view that it be wrong for prospective parents not to use the genome editing procedures for the benefit of their future children.

> *There is nothing ethically wrong with this [procedure] - indeed, if such a procedure were to be found effective, then it would be ethically wrong not to offer it.* (Q1)

British female non-parent, 18-24, Graduate, no genetic condition, not genetically tested

It is the only moral option.
Czech male non-parent, 25-34, graduate, genetic condition in family, not genetically tested

Can you imagine what the child will say when they are older? "So you had the choice to have me healthy but you decided against it?" That would be heart breaking and I think a little cruel… (Q10)
British female non-parent, 25-34, postgraduate, not genetically tested, no genetic condition in family

It is child abuse to bring a weakened child into the world when you could have prevented it. (Q13)
British male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested

7. Diversity

Diversity of different kinds was another issue raised by respondents in reply to a number of survey questions. Some respondents said that heritable genome editing might pose a threat to genetic diversity, which might ultimately give rise to a survival issue (overlapping with ideas about safety and risk).

Since the genetic variant being introduced is shared by most people, we can expect it to be low-risk. Reduction of genetic diversity across the species may be a concern with other modifications. (Q2)
British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

The musical ability gene confers an objective benefit to the child, and if they are genetically inclined to share their parents' interests, they are more likely to have a better relationship. At the same time, there may be a risk that the genetic diversity of the population will be compromised if this modification becomes widespread. As such, it may be that there should be limitations on the number of such modifications made. (Q12)
British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

Again, although this is objectively beneficial to the child, there is a risk that it would compromise genetic diversity if it became too widespread. As such, if scientists judge such a risk to obtain, such treatments should be fairly rationed to prevent said outcome. If the trait has a downside for the child, too, restriction may be wise. (Q13)
British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

Another concern raised by respondents related to social diversity and views about the value of difference were expressed by some respondents

This is different to preventing disease. If we start to engineer humans in this way I worry that we will move toward uniformity and start to eliminate diversity which makes humans interesting. Diversity in a population is what makes us robust. (Q13)
Canadian female non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested

I believe a diverse society is a strong one and that leaving traits like musical ability and scientific ability to chance maintains diversity, the child's autonomy and a society's equality. We need to discuss boundaries as a society for ensuring a

> *balance between the prevention of disease against the "slippery slope of eugenics" ... Again difficult to answer in a sentence!* (Q12)
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

> *Instead of fucking with the genome, let's improve societal tolerance and appreciation of difference.* (Q12)
> *American male parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

8. Naturalness

Ideas about naturalness were expressed in responses to a number of the survey questions; these were manifest in the context of views about what interventions would be likely to be safer or more likely to succeed, about what were understandable or reasonable responses and desires, as well more intuitive or visceral responses to interfering with the natural world. Appeal to the concept of naturalness was also made in the context of denying that heritable genome editing would be wrong because it is 'unnatural'.

It was said that changes made to human embryos using genome editing would be acceptable if they aimed at restoring wild-type genes that were not 'non-natural'.

> *If the genetic alteration were creating a non-natural variant, that would be concerning, as we would then be altering the evolutionary course of the species. But here the "wild-type" variant is being restored, which seems to clearly be a good thing with no negative side effects I can see.* (Q1)
> American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested

It was also suggested that if heritable genetic changes made to cells might occur, or might have occurred, through normal evolutionary processes this should count in favour of such changes being allowed.

> *This is kind of like evolution, so maybe we should be allowed to do this. And this is a case of a real danger. Although it would not be fair to the people who cannot afford this. In the end if the human race is meant to survive, this will happen naturally through evolution.* (Q14)
> *Dutch female parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *This sort of trait might easily evolve naturally - why not introduce it in a way which minimises suffering i.e. all those who can't tolerate drought die so only those that can survive to breed?* (Q14)
> *British male non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

It was also said that altering stem cells with genome editing techniques would deviate too far from 'natural reproduction'.

> *This procedure is too far removed from the natural process of procreation and is even more drastic than genetically editing gametes / embryos. It seems excessive and unnecessary (more in the realm of scientific experimentation).* (Q5)
> *Singaporean female non-parent, 18-24, graduate, genetic condition in family, genetically tested*

And it was suggested that the desire to have genetically related children was understandable insofar as this is what happens in 'natural procreation'.

> *Ali and Brian's main wish is for a child which is genetically related to them (i.e. like what most other couples have as per natural human procreation).* (Q1)
> *Singaporean female non-parent, 18-24, graduate, genetic condition, not genetically tested*

More general or overarching critiques of the use of genome editing to alter future people were made using ideas about naturalness.

> *Too much interference in natural processes (particularly when there is no threat to life) is not necessarily a good thing, and more so when we do not know what the consequences for future generations may be.* (Q2)
> *British female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *There is something more natural-seeming about doing this procedure on Brian (although this may be a perception only), as it seems more like a treatment for his condition rather than an altering of a future person.* (Q4)
> *British female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *This goes against survival of the fittest and is not natural.* (Q14)
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *Tampering with nature.* (Q14)
> *Pakistani female parent, 35-44, postgraduate, no genetic condition in family, genetically tested*

On the other hand some stated explicitly that it was wrong to favour 'natural conception' because it is 'natural' or, equivalently, to oppose the use of genome editing in human reproduction because it is 'unnatural'.

> *I see no reason to discriminate against particular changes to the genome on the basis that they are 'induced' or 'unnatural', particularly given that these changes are (to the best of our knowledge) less likely to be harmful and more likely to be beneficial than your average mutation.* (Q1)
> British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested

> *Nature is a cruel mistress. Random mutations can be as deleterious as anything we would do intentionally and are almost certainly far more so on average.* (Q2)
> British male non-parent, 18-24, college educated, no genetic condition in family, not genetically tested

> *I have a medical research background, but appreciate many will approach this from an uncertainty regarding the unfamiliar, and not always be comfortable with the opportunities genetics may provide. I imagine arguments citing what's natural will feature prominently, but hope to be pleasantly surprised!* (Q16)
> *Demographic data not provided*

9. Relationship between parent and child

A number of related ideas were expressed in response to different survey questions on the nature of parenthood, parents' attitudes towards their child and the relationship between parent and child. These involved notions of ‘begetting’ children, commodification, and designer babies.

> *Again, this would represent a significant step towards the logic of making rather than begetting children.* (Q5)
> *British male non-parent, 35-44, postgraduate, genetic condition in family, genetically tested,*

> *This is the consumer eugenics scenario. This will be socially disastrous because it would massively exacerbate social inequality, allow social prejudices to determine which children get born and turn human beings into designed objects/commodities.* (Q12)
> *British male parent, 55-64, postgraduate, genetic condition in family, genetically tested*

> *These 'designer babies ' would come at a cost and so it would become an elitist practice.* (Q15)
> *Australian female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

10. Relevance of the particular traits edited

Comments in response to different questions suggested that respondents thought that the nature of the genetic alteration proposed was significant. For example, the severity of the condition to which a genetic variation would give rise was relevant to whether genome editing techniques could be used to chance it.

> *By editing "less serious" conditions - or any condition for that matter - it somehow devalues people who have these conditions and are happy with their life. For example, many people with Down's syndrome lead happy fulfilling lives and wouldn't be any other way!* (Q7)
> *British female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Some respondents expressed this as concern with whether or not a change would resemble a medical or normalising procedure, or instead an enhancement.

> *The resulting change is part of range of normal human variation, i.e. it is not introducing something entirely synthetic. The change is not an ‘enhancement’, but introduced to address a specific medical issue.* (Q2)
> *Canadian female parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

> *I really have a problem in deciding between option 1 and 2. Is infertility, or the impossibility to have a healthy child, a disease? If yes, then the procedure should be available for everyone. If no, then there is no reason for the public health system to pay for it. Of course, in this case rich people will have an advantage, but they already have many, so this additional possibility to have healthy babies would make no difference in the general order of things.* (Q9)
> *Italian female non-parent, 35-44, postgraduate, no genetic condition in family, genetically tested*

> *Editing the embryos such that the resulting children benefit from immunity to the disease amounts to an enhancement, rather than a treatment of an underlying condition. As a matter of principle, enhancements are far more drastic than treatments, and do not cross the threshold of permissibility.* (Q11)
> *Singaporean female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

11. *Challenges to the distinctiveness of human reproductive genome editing procedures*

Comments made in response to a number of questions took the form of stating or suggesting that the described applications of genome editing did not differ significantly from other kinds of interventions that most regard to be acceptable. This kind of response was made in a number of contexts. In general terms, some respondents said that intervening in the natural world in different ways is common and widely accepted.

> *Make people healthier and happier! Interfering with nature is what we do all the time, there's absolutely nothing morally wrong with it! Is not difficult!* (Q16)
> *British male non-parent, 18-24, postgraduate, genetic condition in family, genetically tested*

It was said that genome editing would not be distinctive in introducing genetic variations to embryos since this happens in ‘natural reproduction’.

> *Normal sex already introduces dozens if not hundreds of new variants in every new baby without anyone’s consent that are as heritable as this. Why does *this* matter?* (Q2)
> *Spanish male non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

It was said that editing a person’s gametes would be on a par with a fertility treatment.

> *This treatment is no different in principle from any other fertility treatment.* (Q2)
> *British male non-parent, 25-34, Postgraduate, no genetic condition, genetically tested*

Editing cells to make the children they become more resistant to disease struck some respondents as not different in principle to vaccination.

> *Not much different to receiving a vaccine, nothing unethical about making someone immune to a disease.* (Q11)
> *Demographic data not provided*

Editing cells to make the children they become more intelligence similarly struck some respondents as no different in principle to selecting an intelligent partner with whom to reproduce.

> *We already perform a type of selection when we choose a spouse. This is simply more efficient.* (Q13)
> *American female non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

12. *Need for legislative frameworks and monitoring*

The importance of appropriate legislation and need for regulation of any heritable genome editing procedures was raised in response to a number of survey questions.

> *As with all procedures of this kind, there must be legislation in place to protect those undergoing it and to maintain safety standards.* (Q3)

> *French female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *Would need careful regulation by laws of parliament.* (Q5)
> *English female non-parent, 25-34, postgraduate, genetically tested, has genetic condition in family*

> *Ideally, laws should be harmonised internationally.* (Q8)
> *Demographic data not provided*

The need for monitoring and follow-up was raised in response to different questions

> *With proper research and monitored care the pros outweigh the cons.* (Q2)
> *British female parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *Some of the heartache caused by infertility, child illnesses and disease would be lessened. However, there would need to be careful monitoring of this and perhaps restrictions on population growth, perhaps restricting numbers of children.* (Q15)
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

13. Slippery slopes

Respondents broadly opposing genome editing raised concerns about a slippery slope from acceptable to unacceptable uses of the technology, such as those for cosmetic or eugenics purposes.

> *There is a slippery slope when we talk about desirable genetic traits. Particularly when it comes to disability rights, we need to tread very carefully when it comes to these type of issues.* (Q7)
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *Though this would be a 'therapeutic' application, the incremental extension to 'enhancement' techniques in inevitable once this line is crossed.* (Q2)
> *British male parent, 65+, postgraduate, genetic condition in family, not genetically tested*

> *This makes the point about the "slippery slope". Eugenics is not permitted and should never be.* (Q12)
> *British male parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

14. Genetic counselling

The importance of genetic counselling was raised in comments supporting responses to a number of questions. Some respondents who expressed views broadly supportive of human reproductive genome editing said that they did so only on the proviso that individuals or couples were adequately counselled beforehand.

> *After counselling, and embryo must be checked for viability.* (Q6)
> *British female parent, 65+, graduate, no genetic condition in family, not genetically tested*

> *I would be extremely concerned about couples travelling abroad where they may not get the counselling and support they need etc, however it is basically un-policeable. That is why we should allow it in the UK, but with certain provisos about supportive care etc.* (Q8)
> *British female non-parent, 25-24, doctorate, genetic condition in family, not genetically tested*

> *There are risks involved in these procedures therefore it should be down to those individuals involved whether they want to go ahead with it or not, as with giving consent for medical procedures currently. These individuals should be given the appropriate counselling and support throughout their decision.* (Q10)
> *British female non-parent, 25-24, graduate, genetic condition in family, not genetically tested*

15. Bias and infeasibility

Some respondents made comments about bias in the survey questions, suggesting that that the survey unduly limited its description of the relevant scenarios to the circumstances of and effects on the individuals using the procedures and excluded description or discussion of the potential wider societal or other effects.

> *The survey gives almost no background information about why human germline modification is so consequential and controversial. Regarding safety, it says nothing about how germline editing could be "judged to be safe," who would make that call, and what human experimentation or follow-up evidence would be required. It doesn't question whether there is a need for this technology to prevent the transmission of serious inherited disease, given other options available (problematic as those may be) The survey is structured to focus attention on individual couples rather than on societal consequences. It makes no reference to public policy (including the legal prohibitions in effect in 40+ nations), nor to the likely dire impacts on social justice and equity.* (Q16)
> *American male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

> *This survey on the whole is highly biased toward garnering responses that support any and all interventions in the germline. It is a poor tool for assessing public views.* (Q16)
> *American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

> *Why is there no option to say this is never acceptable? This question is biased as it only provides options which favor the treatment. This is NEVER acceptable.* (Q10)
> *American female non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

This sometimes manifested as a complaint about the constraints within, or realism of, the scenarios described. Some suggested these were contrived, contained no description of alternatives to heritable genome editing, such as PGD, or were possibilities, such as the use of heritable genome editing to make human beings resistant to drought, too remote to be worth discussing.

> *This is not a neutral questions – if the reader responses no, they are essentially denying this couple a healthy child. The couple would have the option of PGD, sperm donation or adoption – there is absolutely no reason to edit their future child's genes.*
> *Demographic data not provided*

> *See answers to question 1 and 2. Again, the presentation of information is misleading in failing to mention PGD. Likewise, by oversimplifying the risk, the presentation of information misleads the public. As usual, the overall bias in all of these mistakes tends in the same direction, which is to push the respondent towards their natural tendency to approve medical interventions that prevent suffering. It is the job of bioethics to present the ifs and buts about the use of medical technology, not to reinforce public prejudices.* (Q6)
> *British male parent, 55-64, doctorate, genetic condition in family, genetically tested*
>
> *This is an absurd question and you know it. Including it is a strategic move by the Nuffield staff to generate a strong "no" response, thus indirectly helping legitimate the "yes" responses to the situations described in previous questions.* (Q14)
> *American male parent, 65+, postgraduate, genetic condition in family, not genetically tested*

In the final 'any other comments' question 16 some respondents provided quite detailed feedback on their perceptions of this aspect of the survey, involving discussion of issues relating to stipulations about safety, necessity of genome editing, implications for the value of an 'open future' and inequality.

> *The way in which this public survey is structured and framed is extremely disturbing and disappointing. It seems deliberately designed to produce results that can be claimed as showing "public support" for human germline editing for reproduction. Surely you cannot expect that anyone whose knowledge of the issue is based entirely or mostly on what's provided in the survey would be able to respond in a meaningful way. The survey's three scenarios focus respondents' attention solely on the individual situations and desires of the hypothetical couples contemplating their personal reproductive decisions, with no historical or social context whatsoever. There is a completely unwarranted assumption of "safety," when in reality judgments about what is considered "safe enough" are themselves subject to contestation and disagreement. There is no mention that in the vast majority of cases in which germline editing would be even considered – to prevent the transmission of serious inherited disease – it would be unnecessary (and medically contra-indicated) because of the availability of safer alternatives. There is similarly no acknowledgment of issues of consent – not just of the engineered children being contemplated, but for all future generations of their children as well. The importance of preserving children's "open future" is likewise missing. The survey's failure to acknowledge the potentially dire societal dangers of permitting human germline modification is a very serious shortcoming. There is no consideration of the unlikelihood of actually being able to limit human germline modification to the medical-sounding reasons presented in most of the scenarios. What is far more likely is that permitting it for any reason would lead to a world in which affluent parents could purchase the latest genetic upgrades for their offspring, leading to exacerbation of already existing (and shameful) inequities and discrimination. It takes little imagination to foresee that this could usher in an era in which genetically enhanced "haves" are perceived to be superior to the genetically unenhanced "have-nots" – in other words, an era in which we would witness the emergence of a market-based, high-tech eugenics. Finally, there is no mention that dozens of nations around the world, including most with advanced biomedical / biotech sectors, have deliberated about this issue, and decided to legally prohibit human germline modification. The existence of a binding international treaty that prohibits human germline modification is likewise ignored. This survey is unworthy of the Nuffield Council and its efforts to maintain its international reputation as an independent body. I hope you will decide to discard it and start this aspect of your public consultation from scratch.* (Q16)
> *Demographic data not provided*

Analysis by question

Scenario 1

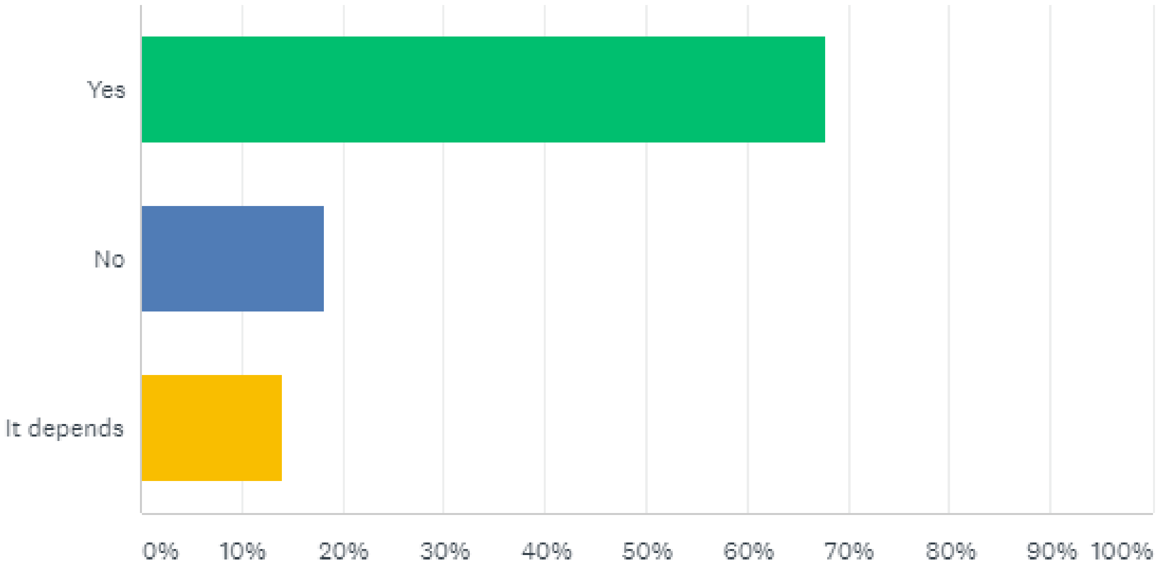
Ali and Brian are a couple in their early 30s, who are hoping to start a family. After two years of trying without success, they decide to seek help from their doctor who refers them to a specialist fertility clinic.

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.

Question 1

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



Yes
216 of 319 respondents (68%)

No
58 of 319 respondents (18%)

It depends
45 of 319 respondents (14%)

Respondents who answered ‘yes’

General positive comments

A number of respondents who provided free text answers to this question indicated generally positive attitudes towards Ali and Brian using the procedure. For example:

> *I’d consider it unethical to deny a couple the chance of children when we have the knowledge and technology to help them.*
> *British female parent, 55-64, doctorate, no genetic condition, genetically tested*

> *… Altering genetic material in order to provide medical (as opposed to aesthetic) advantages is positive in principle.*
> *British male non-parent, 18-24, Graduate, no genetic condition, genetically tested*

> *There is nothing ethically wrong with this - indeed, if such a procedure were to be found effective, then it would be ethically wrong not to offer it.*
> *British female non-parent, 18-24, Graduate, no genetic condition, not genetically tested*

> *The modification of cellular processes to produce fertile cells seems barely controversial.*
> *British male non-parent, 18-24, Graduate, genetic condition, genetically tested*

> *Limited genomic editing for an otherwise fatal to embryo condition seems to be ethically permissible.*
> *British male parent, 35-44, Doctorate, no genetic condition, not genetically tested*

‘No different’ to other forms of genetic change

Some respondents indicated that the type of procedure described to alter Ali’s (A) and Brian’s (B) embryos drew was permissible because the procedure was ‘no different’ to other methods or subjects of genetic change.

> *It is the same as genetic editing in plants and other animals*
> *British male non-parent, 25-34, Graduate, no genetic condition, not genetically tested*

> *Genome editing and heritable changes happen all the time without human direction or with unintended human direction (e.g. there is now evidence that lifestyle and environment could lead to heritable changes in the epigenome). Just like the use of GM elsewhere, well thought out and carefully controlled use is much safer than the evolutionary risk we take with random heritable changes that happen every generation.*
> *British male non-parent, 25-34, Graduate, no genetic condition, not genetically tested*

‘No different’ to other types of fertility intervention

Respondents also suggested that the described procedure was ‘no different’ to other types of fertility intervention.

> *Their right to choose to have children through a straightforward genetic ‘repair’, just the same as any other couple, who may also require medical interventions to have children.*
> *British female non-parent, 55-64, Graduate, genetic condition, genetically tested*

> *I don't see this situation any differently than IVF or other fertilization treatments.*
> *American male parent, 25-34, Postgraduate, genetic condition, genetically tested*

> *I don't think genetic modifications are morally different from other fertility therapies or environmental interventions *in principle*(it matters only for what purpose it is used, not what is used).*
> *Spanish male non-parent, 18-24, Graduate, genetic condition, not genetically tested*

> *The procedure is not drastically different from mitochondrial replacement, in that there is an alteration to the genetic composition of the embryo.*
> *British male non-parent, 25-34, Postgraduate, no genetic condition, not genetically tested*

Their 'only chance' to have a genetically-related child

Several respondents suggested that the procedure described in the scenario should be permitted in principle because it provided Ali and Brian with their only chance to have a genetically-related child.

> *Ali and Brian's main wish is for a child which is genetically related to them (i.e. like what most other couples have as per natural human procreation).*
> *Singaporean female non-parent, 18-24, Graduate, genetic condition, not genetically tested*

> *If they really want a child of their own, this procedure enables them.*
> *British female non-parent, 18-24, Doctorate, no genetic condition, not genetically tested*

> *…This couple should have the opportunity to have a child of their own.*
> *British female non-parent, 25-34, Graduate, genetic condition, not genetically tested*

> *They had no other options for biological children.*
> *American male non-parent, 25-34, Graduate, no genetic condition, not genetically tested*

Reproductive choice

Some respondents mentioned reproductive rights, specifically, in this scenario.

> *Ali and Brian should have reproductive freedom, which is a fundamental human right.*
> *American male non-parent, 18-24, Postgraduate, genetic condition, not genetically tested*

> *The fact that the embryo is being genetically changed so that it has an allele that most people have is important to me as it promotes equality.*
> *British female non-parent, 0-17, Secondary School, no genetic condition, not genetically tested*

Other respondents focused on reproductive freedom.

> *We each should have the freedom to decide how our gametes are altered.*
> *British female non-parent, 35-44, Doctorate, no genetic condition, not genetically tested*

> *Everyone should have the chance to get a baby.*
> *British female non-parent, 18-24, Graduate, genetic condition, not genetically tested*

> *Biological parenthood is an important human interest.*
> *Italian male parent, 25-34, Graduate, no genetic condition, not genetically tested*

Freedom more generally were also cited by respondents in support of their response.

> *Basic freedom. They are consenting and informed adults, no third party is harmed, so they should be allowed to do what they want.*
> *American male non-parent, 35-44, Doctorate, genetic condition, not genetically tested*

> *We each should have the freedom to decide how our gametes are altered.*
> *American female non-parent, 35-44, Doctorate, no genetic condition, not genetically tested*

> *Individual freedom is a primary value.*
> *Demographic data not provided*

The importance of reproductive choice and autonomy was also highlighted by respondents' free text submissions.

> *It is their choice, if they are happy to take the risk,that is all that matters.*
> *British female non-parent, 25-34, Postgraduate, genetic condition, genetically tested*

> *The idea that they would prefer a child who is genetically related to them seems problematic in and of itself, but that is not enough of a reason to restrict their reproductive autonomy.*
> *American female non-parent, 18-24, Postgraduate, no genetic condition, not genetically tested*

> *They own their bodies and can take whatever risks they decide appropriate for themselves.*
> *American male non-parent, 25-34, Postgraduate, genetic condition, genetically tested*

Consent

The relevance of consent in the scenario was highlighted by a number of respondents who felt that it should be permitted to alter Ali and Brian's embryos in principle.

> *So long as everything has been explained to them and they fully understand all the pros and cons and they make the decision to go ahead, then in my opinion they should not be deprived of this chance.*
> *British male non-parent, 65+, Secondary school educated, no genetic condition, not genetically tested*

> *… Assuming the couple have been informed in a balanced way of the risks and benefits and have thus given informed consent to proceed, there seems to be no reason to reject the procedure for them."*
> *Demographic data not provided*

> *So long as their choices are voluntary and consensual, they have a moral right to make that decision.*
> *American male non-parent, 25-34, Postgraduate, genetic condition, genetically tested*

The characteristics of the future child

Several respondents' free text responses focused on the significance of the features of future child conceived as a result of the procedure. Some respondents noted, for example, that the resulting child's characteristics would not be changed if the procedure were to be permitted.

> *Iit is a gene which does not determine character or appearance.*
> *Czech male non-parent, 25-34, College educated, genetic condition, not genetically tested*

> *They are not changing the characteristics of the child, just the method in which the egg is fertilised.*
> *British female non-parent, 25-34, Postgraduate, no genetic condition, not genetically tested*

> *The child's genetic makeup wouldn't be altered.*
> *Canadian female parent, 55-64, Postgraduate, genetic condition in family, not genetically tested*

> *… It's not altering a condition a child may have just hopefully enabling a child to be conceived.*
> *Demographic data not provided*

> *This is also not a change that would sacrifice the autonomy of the future child.*
> *British female non-parent, 0-17, Secondary school educated, no genetic condition, not genetically tested*

Financial, social justice, and resource allocation considerations

Some respondents raised points about the availability of the procedure and implications for healthcare resources.

> *… Would this be limited as with PGD to a certain number of cycles on the NHS?*
> *British female non-parent, 25-34, Postgraduate, no genetic condition in family, genetically tested*

> *Considering the limited resources of medical research and health services, I don't agree with putting much effort and money in reproduction research/healthcare. I don't see infertility as a "real" health problem.*
> *Italian male non-parent, 35-44, Graduate, genetic condition in family, not genetically tested*

> *Whether a public health system should provide this is for me the biggest question. Not convinced.*
> *British female non-parent, 45-54, Doctorate, no genetic condition in family, not genetically tested*

Access and social justice considerations were also raised by respondents.

> *[The] opportunity afforded to Ali and Brian should be made available to all people who would want/need to go through the procedure, regardless of income.*
> *American female non-parent, 25-34, Doctorate, no genetic condition in family, not genetically tested*

> *… this procedure, because it is liable to be expensive, may not be available to all persons. We must then ask whether this is acceptable, in other words whether reproduction for persons without the ability to reproduce non-technologically should be a matter of pay-if-you-can.*
> *American male parent, 35-44, Doctorate, genetic condition in family, not genetically tested*

> *How will this affect reproduction rate of rich vs. poorer people? This needs to be further examined.*
> *German male non-parent, 35-44, Graduate, no genetic condition in family, not genetically tested*

Safety and risk

Some respondents referred to the safety of the procedure described in the scenario, in some cases indicating that it was a conditional term of their positive response to this question.

> *If the procedure is deemed safe, I see no reason for it not to be made available to them.*
> *French male non-parent, 18-24, Postgraduate, no genetic condition in family, not genetically tested*

> *If the procedure is considered to be safe, I see no reason for not allowing it.*
> *Italian female non-parent, 35-44, Graduate, genetic condition in family, not genetically tested*

> *…As long as there are no chances or very limited ones, comparable to those that a normally conceived embryo would have, that abnormalities or medical problems will not arise in the future baby.*
> *British female non-parent, 25-34, Graduate, no genetic condition in family, not genetically tested*

> *As the procedure is safe and effective, the risks are no greater than with any procedure and assuming the couple have been informed in a balanced way of the risks and benefits and have thus given informed consent to proceed, there seems to be no reason to reject the procedure for them.*
> *Demographic data not provided*

Similarly, other respondents qualified their answers by noting the potential risks of using the procedure. One type of response focused on risk to the resulting offspring.

> *Dependent on risk to the embryo - i.e. birth defects etc. if acceptable risk then no reason why it can't be done.*
> *British male non-parent, 25-34, Doctorate, genetic condition in family, not genetically tested*

> *Whatever helps them to have a "healthy" child, while deemed to have low risks, should be allowed.*
> *British female non-parent, 25-34, Postgraduate, no genetic condition in family, not genetically tested*

> *Any risk to the embryos is small as if it does not work, they would only die/be destroyed anyway, as is happening to them already.*
> *British female non-parent, 18-24, Graduate, genetic condition in family, not genetically tested*

> *The reservation I would have here would be whether there are any ill effects that may be suffered by the child down the line - and whether we would really know how safe the procedure is.*
> *British female non-parent, 25-34 Doctorate, genetic condition in family, not genetically tested*

Risk for Brian, in addition to the resulting child, were also raised.

> *Unlike other fertility procedures, it seems liable to impose a relatively small risk on the resulting child or on Brian. Many assisted reproductive technologies impose risk due to the use of hormones which can increase cancer risk, cause discomfort, and so forth.*
> *American female parent, 35-44, Doctorate, genetic condition in family, not genetically tested*

Harm

Relatedly, the likelihood of harm being caused by the procedure described in the scenario was also raised by respondents as a consideration in permitting the procedure in principle.

> *There is no likely harm to the parents, nor child.*
> *British male non-parent, 18-24, Postgraduate, no genetic condition in family, not genetically tested*

> *I can see no harm that could result from this, and it would be most likely to bring happiness to Ali and Brian.*
> *British male parent, 65+, Graduate, genetic condition in family, not genetically tested*

> *It harms no one, helps them, helps the embryo.*
> *British male parent, 25-34, Graduate, no genetic condition in family, not genetically tested*

Need for guidance

Respondents also highlighted the need for guidance in any decision to permit the procedure.

> *… Each case should be decided by a diverse panel of experts.*
> *British female non-parent, 25-34, Doctorate, genetic condition in family, not genetically tested*

> *There must be sufficient guidance about the type of situations in which this technology is applicable, and when it is not.*
> *Canadian female non-parent, 25-34, Doctorate, no genetic condition in family, genetically tested*

Respondents who answered ‘no’

Challenge to the idea that genetic parenthood is important

Several respondents suggested that their negative answer to this question stemmed from their views that genetic parenthood should not trump every other consideration.

> *If Ali and Brian wish to become parents they do not need to have one that is genetically related to them.*
> *British, does not identify as male or female, non-parent, 25-34, Graduate, no genetic condition in family, genetically tested*

> *Genetics is not the only consideration for family construction.*
> *American female non-parent, 55-64, Postgraduate, genetic condition in family, not genetically tested*

> *…Having genetically related children is not a medical benefit either to the child or parent.”*
> *British male parent, 55-64, Doctorate, genetic condition in family, genetically tested*

> *I don't feel genetics are essential to "becoming a parent"; plenty of parents are not genetically related to their child.*
> *British female non-parent, 25-34, Postgraduate, genetic condition in family, not genetically tested*

> *[I] am dubious about the alleged moral value of raising offspring who are genetically directly related.*
> *Australian female non-parent, 35-44, Doctorate, no genetic condition in family, not genetically tested*

> *While I understand that many people want to have children that are genetically related, this "want" is not a "right" and does not trump all other interests.*
> *Canadian-British female parent, 55-64, Doctorate, no genetic condition in family, not genetically tested*

Availability of other reproductive options

Respondents who answered this question negatively also made the argument that Ali and Brian had 'plenty of other options to have children'. One option raised was gamete donation.

> *There are alternative options available for the couple to have a family (donor sperm etc.)*
> *British female non-parent, 25-34, Graduate, no genetic condition in family, not genetically tested*

> *Existing sperm banks could provide this couple with sperm.*
> *American female non-parent, 55-64, Postgraduate, genetic condition in family, not genetically tested*

> *While it would be a "nice thing" they could reality adopt, use a sperm donor, or go other routes.*
> *Canadian female non-parent, 55-64, Postgraduate, genetic condition in family, not genetically tested*

Adoption was also suggested as an alternative to undertaking the procedure set out in the scenario.

> *They can adopt.*
> *Australian female non-parent, 45-54, Postgraduate, genetic condition in family, genetically tested*

> *If they are unable to have a child they should turn to adoption and understand that passing on their genetic material is really not a big deal, while bringing up a human being is more important.*
> *Bulgarian female non-parent, 18-24, Doctorate, no genetic condition in family, not genetically tested*

> *… There is also the option of adoption, despite lack of biological relation; and under present circumstances of a surfeit of orphans, this would be the more ethical choice.*
> *American male parent, 55-64, Graduate, genetic condition in family, not genetically tested*

Concerns about germline modification

Several free text responses highlighted issues with modifications to the germline, specifically, linking this other issues such as consent, eugenics, safety.

> *…In principle, this is a germline modification and there is a widespread opposition among many people to such alterations.*
> *American female non-parent, 55-64, Postgraduate, genetic condition in family, not genetically tested*

> *… Gene editing on the germline (gametes and embryos) does not currently provide the required safety guarantees on the possible side effects attributable to undesirable genetic abnormalities that can occur during the process, and which would be transmitted to future generations.*
> *Demographic data not provided*

> *Germ line editing is unsafe as well as unethical. The 'future' person has not consented. We cannot say that the procedure is safe; there are risks of collateral genetic mutations as a result of the editing process.*
> *British male parent, 65+, Postgraduate, genetic condition in family, not genetically tested*

> *Allowing germline modification opens the door to a new techno-eugenics that cannot be controlled and that would rip the human species asunder.*
> *American male non-parent, 65+, Doctorate, no genetic condition in family, not genetically tested*

Impact on/welfare of the future child

More specifically, some respondents focused on the potential effects on the resulting offspring.

> *The integrity of the child's genome, as a future adult with their own life, should not be manipulated by parents to fulfil their emotional needs or the experimental desires of doctors.*
> *British male non-parent, 45-54, Postgraduate, genetic condition in family, not genetically tested*

> *It is unknown what effects the procedure will have on the child.*
> *British male non-parent, 45-54, Postgraduate, genetic condition in family, not genetically tested*

> *… There are too many unknowns, particularly with the unborn child's health. The long-term risks outweigh the potential benefit to undergo this.*
> *British female parent, 25-34, Graduate, genetic condition in family, not genetically tested*

> *As there is no guarantee of success and there may be a risk for the embryo, not for the father, it would be better to be prudent and delay the procedure till there is not extra risk for the embryo.*
> *Argentinian female parent, 45-54, Doctorate, genetic condition in family, not genetically tested*

Concerns about discarded embryos

Concerns around the use of multiple embryos in the procedure were also raised by respondents who answered this question negatively.

> *… Several embryos would most likely be generated in the application of the procedure, from which the most suitable ones would be selected to be implanted in the mother, and the rest would be destroyed. It is not*

> *ethically justifiable to bring an individual to life when the cost is the life of many of his brothers and sisters.*
> Demographic data not provided

> *I would also be concerned about the handling of any 'unwanted' embryos from the procedure.*
> Dutch-Ghanian female non-parent, 45-54, Graduate, genetic condition in family, not genetically tested

Consent

The fact that the future child could not consent to the procedure was also noted in free text responses to this question.

> *The interests of the foetus / child / person come first and she cannot consent in these circumstances.*
> Australian male non-parent, 65+, Postgraduate, genetic condition in family, not genetically tested

> *The 'future' person has not consented.*
> British male parent, 65+, Postgraduate, genetic condition in family, not genetically tested

Public resource considerations and access

Some respondents who indicated that the procedure should *not* be permitted highlighted financial considerations relating to offering the procedure, and relatedly, inequalities in how it might be made available.

> *There should be no government money spent on gene editing technologies as a means of treatment of infertile couples.*
> Bulgarian female non-parent, 18-24, Graduate, genetic condition in family, not genetically tested

> *I would rather see the considerable resources that it would take to enable this technology put into facilitating other parenting options such as carefully vetted adoption processes.*
> Australian female non-parent, 45-54, Doctorate, genetic condition in family, not genetically tested

> *Having children is a luxury and not a right.*
> Dutch female non-parent, 18-24, Graduate, genetic condition in family, not genetically tested

> *This procedure might cause inequalities between people who cannot use it for some reasons (financial, family disagreement, religious, cultural etc.).*
> Polish female non-parent, 25-34, Doctorate, no genetic condition in family, not genetically tested

Respondents who answered ‘it depends’

It depends on safety

Several respondents said that the answer to this question depended on the safety of the procedure:

> *It depends on what 'safe' means.*
> *British male non-parent, 35-44, Doctorate, genetic condition in family, not genetically tested*

> *The decision to permit the procedure should depend upon the nature of the evidence underlying the assumptions that the procedure is both successful and safe.*
> *British female parent, 45-54, Doctorate, genetic condition in family, not genetically tested*

> *If the procedure is "safe" for both parent and offspring, in the sense that there is no reason to think the parent or resultant child will be harmed by this procedure, then I think it should be permitted.*
> *British female non-parent, 18-24, Postgraduate, genetic condition in family, not genetically tested*

Respondents also discussed how animal research might be involved in an assessment of the safety of the procedure.

> *Only if it's safe and has been done before in animal model, where it was shown to be precise.*
> *Russian female parent, 35-44, Doctorate, no genetic condition in family, not genetically tested*

> *In animal studies, have successive generations been tested?*
> *British female parent, 45-54, Doctorate, genetic condition in family, genetically tested*

It depends on risk

Several respondents indicated that their answer to the question would depend on the risks associated with the procedure, with a particular focus on risk to the future child.

> *It depends on the risks involved for the child that is being produced.*
> *Australian male non-parent, 25-34, Postgraduate, no genetic condition in family, not genetically tested*

> *Will there be any risk to the developing foetus?*
> *British female non-parent, 45-54, Doctorate, genetic condition in family, not genetically tested*

> *If the risks include serious abnormalities, whether physical or mental, then the issues for the foetus and later the baby outweigh any benefits.*
> *British/Australian male non-parent, 35-44, Doctorate, genetic condition in family, not genetically tested*

> *It depends on the level of certainty around the possible bad effects for any resulting child. How certain are we that the modification of the genome will not cause some other abnormality which the child will then carry, either silently in its own genome (perhaps to appear in a subsequent generation) or in the phenotype.*
> *British male non-parent, 55-64, Doctorate, genetic condition in family, not genetically tested*

Risk for future generations was also highlighted by some respondents.

> *There is no precedent for modifying the genes of a human embryo. These changes will most likely be heritable, and thus will affect future generations. Although this is about enabling a couple to have genetically related children, it opens the door to modifying the genome, which might be better left closed.*
> *American male non-parent, 35-44, Doctorate, genetic condition in family, not genetically tested*

It was also suggested that the acceptability of risk might change depending on whether it applies to A and B rather than their resulting offspring.

> *If the risks were mostly to the parents rather than the embryo, this would be more acceptable as they are capable of giving consent. If the risks included failure of the embryo to develop, this would be more acceptable than the risk that a child would be born with severe defects as a result of this procedure.*
> *Demographic data not provided*

More research is needed

Respondents also suggested that there would be benefits from long-term research.

> *I think that more long-term studies are required before I am willing to accept this type of intervention. Particularly, altering genetics of a population in such a quick manner can have unintended consequences that reach far beyond the one species being treated.*
> *American male non-parent, 25-34, Graduate, genetic condition in family, not genetically tested*

> *I suppose that I would want to know more about the long-term consequences are before saying yes.*
> *Australian female non-parent, 18-24, Graduate, no genetic condition in family, not genetically tested*

Public resource considerations and access

Financial cost as a condition of permissibility was also noted in a number of submissions.

> *It depends on the cost of the treatment*
> *British female non-parent, 55-64, Doctorate, no genetic condition in family, genetically tested*

> *…The relative cost and commitment of resources should be considered.*
> *British female parent, 45-54, Doctorate, genetic condition in family, not genetically tested*

> *The cost-effectiveness of the procedure in comparison to other options e.g. sperm donation (particularly if treatment being offered is state-funded).*
> *Australian female non-parent, 45-54, Doctorate, genetic condition in family, genetically tested*

> *When medicines are being denied to cancer patients on the basis of cost, when there are insufficient medical facilities for the elderly, then there has to be evaluation of the cost and a decision made about payment. This is not a life threatening situation so it must be weighed against what else could be done with that money.*

> British female parent, 55-64, Postgraduate, genetic condition in family, genetically tested

A question around how individuals might access the procedure set out in the scenario was also raised.

> *If the procedure were to be available as an NHS treatment what would the cost be and how would access to this treatment be allocated?*
> British female parent, 55-64, Postgraduate, genetic condition in family, genetically tested

> *If the service is being provided publicly to all and regulated via a democratic process.*
> British male non-parent, 25-34, Postgraduate, no genetic condition in family, not genetically tested

Challenge to the idea that genetic parenthood is important

Some respondents raised questions concerning the significance of genetic parenthood

> *Why the emphasis on having a genetically related child? (Noting this seems to be something that is prioritised over other issues.)*
> Australian female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested

> *Having a genetically related child is not a right and the reasons for obtaining one is to be questioned in order to determine the motivation behind it. What must be avoided is a "consumer's perspective".*
> Canadian male parent, 55-64, postgraduate, genetic condition in family, genetically tested

> *If they're infertile they should just adopt instead and not pass on their faulty DNA, but if it means a lot to them to have a genetically related child then the procedure should be allowed.*
> British male non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested

> *… If there are infants waiting to be adopted and the treatment is expensive then it wouldn't be just to offer this treatment when it would be better for society to encourage raising non-genetically related children.*
> British female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested

Need for more information

Some respondents in this category raised questions about the scenario as described suggesting that more information was needed in order to come to a conclusion.

> *How many embryos will be produced during the procedure? What will happen to the unused embryos if they are viable?*
> British male non-parent, 18-24, graduate, genetic condition in family, not genetically tested

> *Do they have children from previous relationships?*
> British female parent, 55-64, college educated, no genetic condition in family, not genetically tested

> *Would the procedure affect just the embryo itself making it possible for it to develop like "normal" embryos or what? Would there be changes to the resulting child's DNA that would be passed on to future generations or not?*
> British male parent, 65+, postgraduate, genetic condition in family, not genetically tested

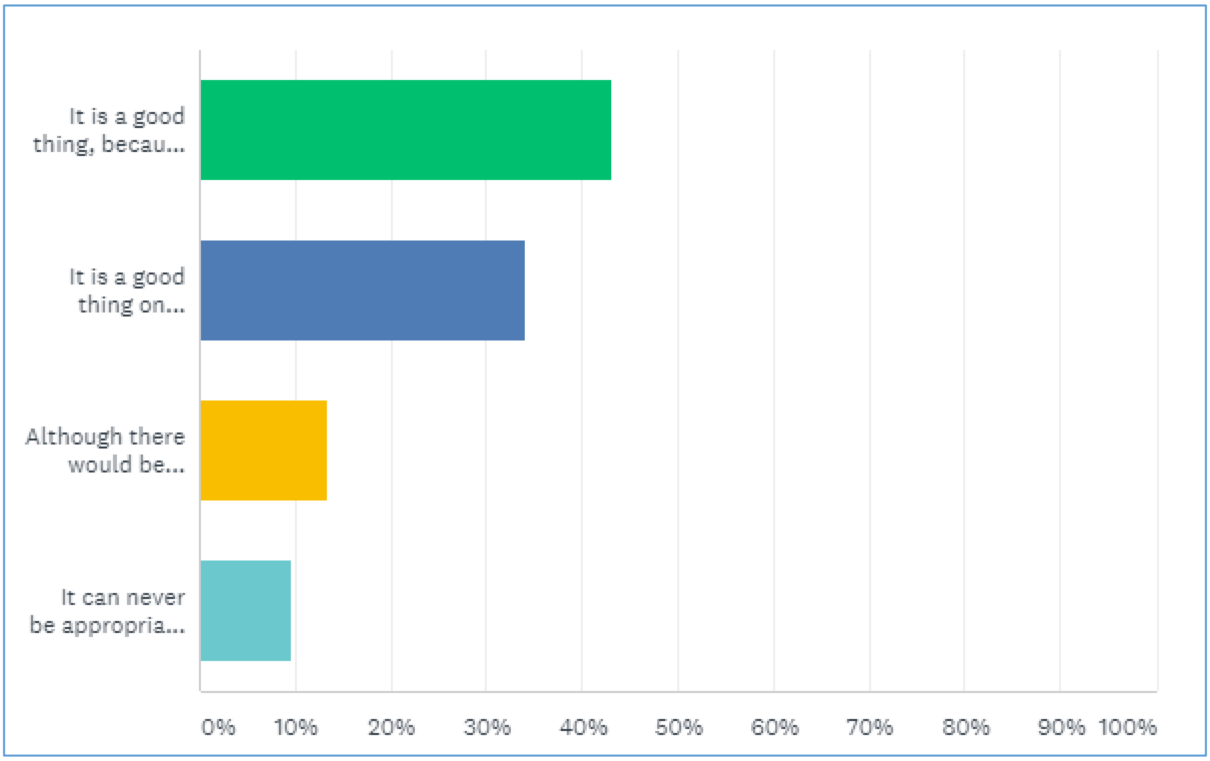
Availability of other options

Another point raised was alternative options to use of the procedure should be first considered.

> *Perhaps more options should be presented to the couple, such as adoption.*
> *British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

Question 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
135 of 314 respondents (43%)

It is a good thing on balance, although there are some concerns about making changes that will be inherited by future generations
107 of 314 respondents (34%)

Although there would be benefits, these are outweighed by concerns about making changes that will be inherited by future generations
42 of 314 respondents (13%)

It can never be appropriate to interfere with genes in a way that will be passed on to future generations
30 of 314 respondents (10%)

Respondents who answered ‘It is a good thing, because future generations will be free of the condition affecting Brian’s fertility’

Health benefits for future generations

The possibility of removing health problems for future generations was raised by a number of respondents in support of their answers.

> *If the future generations inherit the introduced genetic variant then they won’t have to go through the same difficult process and emotional difficulties of not being able to have a child the way Brian and his wife did.*
> *South African female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *Clearly the mutant condition should not be passed on again if it is clear it only causes problems for future generations.*
> *Singaporean male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *If the change is beneficial, I’d argue it’s favourable that it’s passed onto future generations to avoid them having the same issues.*
> *British male non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested*

> *Better to have a future with no genetic disease.*
> *Welsh female non-parent, 18-24, college educated, genetic condition in family, not genetically tested*

Other respondents highlighted health benefits more generally, without reference to future generations.

> *It is purely a good thing to remove detrimental conditions from the gene pool as long as no coercion is involved.*
> *American male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *The elimination of genetic disorders should be welcomed.*
> *British male non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *Modifying DNA in this way can greatly benefit public health.*
> *British male non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

No different’ for many generations versus one generation

A view was expressed that there is no difference in the acceptability of making a genetic change for one generation and in making it in many generations.

> *If it is acceptable in one generation surely it must be acceptable beyond that generation. There would be no logic in making a distinction.*
> *British male non-parent, 55-64, graduate, no genetic condition in family, not genetically tested*

> *If it was best for the parent, how can it not also be best for the children?*
> *British male parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

The change would be on a par with other (acceptable) forms of genetic alteration

Respondents also suggested that the method by which genetic changes were made were ‘no different’ to other – in their views, acceptable – forms of genetic alteration.

> *Changes to future generations occur all the time through random mutations, exposure to EM waves, epigenetics (diet, stress - particularly during pregnancy). All these will affect future generations, often in negative ways. I see no reason to discriminate against particular changes to the genome on the basis that they are ‘induced’ or ‘unnatural’, particularly given that these changes are (to the best of our knowledge) less likely to be harmful and more likely to be beneficial than your average mutation.*
> *British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *All reproduction involves interference with genes.*
> *American male non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *Normal sex already introduces dozens if not hundreds of new variants in every new baby without anyone’s consent that are as heritable as this. Why does *this* matter?*
> *Spanish male non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

Some respondents specifically drew attention to so-called natural genetic changes in support of their answer.

> *We naturally inherit changes, or novel changes are created when we are that we pass on to future generations all of the time.*
> *Demographic data not provided*

> *Predicting and using technology in genetics is no more harm than the selection we are doing in plant / animal species already for the benefit of human nutrition. Natural selection will still do its job here and the offspring with the variant will or will not survive other challenges.*
> *Greek female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *Nature is a cruel mistress. Random mutations can be as deleterious as anything we would do intentionally and are almost certainly far more so on average.*
> *British male non-parent, 18-24, college educated, no genetic condition in family, not genetically tested*

Absence of harmful effects

Also in support of their answer to this question, some respondents referenced an absence of evidence on adverse effects that could occur as a result of the procedure.

> *So far there’s no evidence to suggest this gene will cause abnormalities.*
> *British male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *So long as the genetic variant change does not adversely affect health, personality etc.*
> *British male non-parent, 65+, graduate, no genetic condition in family, not genetically tested*

> *From the information given, the genetic condition being edited out serves no other function, or has no other manifestation, besides preventing normal, healthy pregnancy. So, in editing the gene to the most common variety, only serves to increase options in subsequent generations (birth children or not), with no perceived costs.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Obtaining 'normality'

Some respondents suggested that the modification described would produce a common or naturally-occurring gene, leading to a 'normal' variation.

> *The DNA sequence is being changed back to a "normal" variation where his was originally mutated.*
> *British male non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *Future generations will inherit a normal variant, just like most of the population.*
> *British female non-parent, 55-64, graduate, genetic condition in family, genetically tested*

> *Correcting a faulty gene does not create a new class of person, this is not an artificial genome but simply replacement of a faulty sequence with a healthy sequence already seen in the population demography.*
> *American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

> *If the genetic alteration were creating a non-natural variant, that would be concerned, as we would then be altering the evolutionary course of the species. But here the "wild-type" variant is being restored, which seems to clearly be a good thing with no negative side effects I can see.*
> *American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

'Why wouldn't you?'

A number of respondents responded rhetorically in their free text responses to this question, adopting a stance that can be captured by the question 'why wouldn't you?'

> *I can't think of a reason why you wouldn't want to pass on a beneficial gene edit to your children.*
> *British female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *Why on earth would anyone want to give to future generations that which we have determined as bad for our generation?*
> *British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

> *There isn't a good reason to keep deleterious mutations if we have the technology to safely eliminate them.*
> *American female non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

Under certain conditions

Some respondents attached conditions to their positive answers. Factors cited as significant included the frequency in the wider population of the variant that the procedure would produce, whether material from the procedure would remain in the future child's genome, and that the situation was monitored, amongst others.

> *As long as the changes introduced are those that most people have then fine.*
> *American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

> *I would be concerned only if there was something left in the genome from the edit. If the edited sequence was exactly the same as the non-mutant gene I see no problem in it bring inherited.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *A record should be kept of the fact that the person has had the procedure, in case some, at present unknown, collateral harm should be discovered.*
> *American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

> *Assuming there are no unintended phenotypes*
> *Demographic data not provided*

> *This case specifically corrects a condition which is presumably not associated with an identity or considered a disability, so for future to inherit the changed genetic material is not problematic.*
> *American female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

Diversity

A caveat made by one respondent was that if the genetic diversity of the population were to lessen as a result of use of procedures of this time, this would raise issues.

> *Since the genetic variant being introduced is shared by most people, we can expect it to be low-risk. Reduction of genetic diversity across the species may be a concern with other modifications, but since Brian's variant is not heritable anyway, that concern is moot.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Respondents who answered 'It is a good thing on balance, although there are some concerns about making changes that will be inherited by future generations'

Uncertainty about long term consequences

Several respondents stated that their concerns related to uncertainty around the future consequences of the genetic change described in the scenario.

> *The extent of the interactions these changes could have with the rest of the genome are unknown.*
> *Scottish female non-parent, 18-24, college educated, no genetic condition in family, not genetically tested*

> *We are not sure how these alterations may affect us in the future, so while it may be a good opportunity in the short term, rigorous follow-up is required to track the changes.*

French female non-parent, 18-24, graduate, genetic condition in family, not genetically tested

> *… If the gene had an epigenetic change, due to environmental influences, there may be unexpected consequences.*
> *Demographic data not provided*

> *We don't really know the full effect of making the change, so the precautionary principle should apply.*
> *British male parent, 65+, graduate, genetic condition in family, genetically tested*

Impact on future generations

Concerns were also highlighted for potential risks specifically to future generations.

> *…It could become very risky to genetically alter future generations without a full idea of how that would impact society.*
> *American female parent, 65+, postgraduate, genetic condition in family, not genetically tested*

> *…There may be a risk that the method used to introduce the variant will have off-target effects and introduce other alterations to the genome whose consequences will be less easy to predict. Some of these alterations may not have an obvious phenotype at first, e.g. age-related conditions, recessive mutations, which may only become apparent after they have already been passed on to children."*
> *Demographic data not provided*

> *Given that genetic changes ripple out and eventually reach all humans, the number of people who undergo gene therapy that might pass on to other generations should be highly limited.*
> *British male parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *My main concern is with the immediate next generation, and side effects. Only then would I worry about subsequent generations. However, the fact that they could potentially be impacted means that they cannot be ignored in ethical reasoning.*
> *American female parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

Consent

> *I don't see why somebody would want to carry a mutation that has a serious impact but we are somehow playing God by changing the genome of future generations without their consent.*
> *French male non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *I would say that informed consent is the deciding factor here, such that provision is made that their child is able to understand their choice as well.*
> *American male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Need for further research and evidence

A number of respondents said that greater levels of evidence on the type of genetic change outlined in the scenario were required.

> *… More research should be done to examine whether such a genetic abnormality may also contain certain genetic benefits before the procedure is rolled out.*
> *British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *With proper research and monitored care the pros outweigh the cons.*
> *British female parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *As with mitochondrial replacement, there should be long-term studies on the impact of changes to nuclear DNA on subsequent generations before the procedure could be considered relatively safe.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *All depends on the side effects and precision of the procedures that should be determined prior to implementing the methods.*
> *Canadian male parent, 55-64, postgraduate, genetic condition in family, genetically tested*

The purpose of the change is acceptable

Some respondents thought that nature of the proposed genetic change was important.

> *Ali and Brian's case is rare and limited to treating a fertility disorder in the father (rather than treating a genetic disease in the child more generally). This argument would be strengthened if the genetic alteration was made to Brian's sperm rather than to the embryo. I think this justifies Ali and Brian's case crossing the high threshold of permissibility.*
> *Singaporean female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *If not having the variant means an 'abnormal' pathological trait (i.e. infertility) then I have no issue with it..*
> *British female non-parent, 18-24, postgraduate, genetic condition in family, genetically tested*

> *The resulting change is part of range of normal human variation, i.e. it is not introducing something entirely synthetic. The change is not an 'enhancement', but introduced to address a specific medical issue.*
> *Canadian female parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Respondents who answered 'Although there would be benefits, these are outweighed by concerns about making changes that will be inherited by future generations'

Uncertainty about long term consequences

A lack of knowledge about the long term effects of use of the technique as set out in the scenario featured as a concern in a number of respondents' comments.

> *We have inadequate experience with such modification of DNA and there has not been sufficient ethical, scientific and spiritual considerations in society permitting such modifications.*
> *Canadian male parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

> *How confident are we that these genes are not involved in other phenotypic manifestations beyond the fertilization problem? And again, what kinds of changes will we allow beyond rectifying the fertilization problem?*
> *American male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *Genetic alterations account for what we know today, which may be limited as to the type of safety and efficacy evaluated. The risks from the unexpected have to be factored into the decision, and ignorance of the unexpected has prevailing weight against permissibility.*
> *Indian male parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

> *… The science is too new to know long term effects.*
> *British female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *…We don't know the long term effects of these changes, so it would be an experiment, and these children did not give consent for that.*
> *Dutch female non-parent, 18-24, graduate, no genetic condition in family, not genetically tested*

Need for further research

Similarly, respondents also stated that their concerns were due to a perceived lack of evidence on the technique described in the scenario.

> *There is no evidence how these changes may affect future generations, so a carefully clinical follow-up in mandatory.*
> *Argentinian female parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

> *The concerns outweigh the benefits at the moment. But perhaps there will be advances and evidence to settle such concerns.*
> *British male parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

Concerns for future generations

Concerns for future generations were raised by a number of respondents.

> *Passing on altered genes to future generations could have irreversible (and potentially negative) unforeseen consequences.*
> *British male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *I would question the eventual outcome of the procedure... will there be any repercussions for future generations?*
> *American male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *The future generations did not ask to have changes in their DNA so it should not be allowed. In this case they would not exist if the changes hadn't been made so this makes it a bit more complicated.*
> *Dutch female non-parent, 18-24, graduate, no genetic condition in family, not genetically tested*

Safety concerns

More general safety concerns were also highlighted by respondents.

> *As well as correcting a certain genetic defect, unpredictable genomic alterations can occur during the process that are not sufficiently well controlled at present.*
> *Demographic data not provided*

> *I'm concerned about unintended genetic changes/off-target-effects with symptoms later in life.*
> *German female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

Interfering with the 'natural'

Questions about maintaining the 'natural' were also raised by respondents.

> *Altering natural selection ain't very appropriate.*
> *Demographic data not provided*

> *Too much interference in natural processes (particularly when there is no threat to life) is not necessarily a good thing, and more so when we do not know what the consequences for future generations may be.*
> *British female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

Slippery slope

Concerns about a slippery slope towards inappropriate uses of the procedure also featured in a response to this question.

> *…What kind of changes will we allow beyond rectifying the fertilization problem?*
> *America male non-parent, 25-34, doctorate genetic condition in family, not genetically tested*

> *I am concerned about the 'slippery slope' - once it is possible to modify parts of the genome in the germline, how do we decide what is and is not an appropriate modification?*
> *Demographic data not provided*

Social stratification

Concerns around the possibility that society would end up split into those who could, and could not, afford to make use of the procedure.

> *… If people have to fund their own treatment, it leads to a two tier situation, whereby those that can afford it can have babies, and those who can't afford such treatment, can't have babies.*
> *British female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

Respondents who answered 'It can never be appropriate to interfere with genes in a way that will be passed on to future generations'

Uncertainty about long term consequences

Some respondents highlighted their concerns that the effects of the procedure outlined in the scenario were unknown.

> *Off-target effects are unknown.*
> British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested

> *We don't even know how the genetic code works! Anomalous results are continually being discovered and investigated. "Never" is a decent approximation of when we'll know enough technically to begin this discussion; now is totally inappropriate.*
> American male non-parent, 65+, postgraduate, genetic condition in family, not genetically tested

> *Heritable 'fixes', like all other technologies and techniques, pose unpredictable costs, risks and hazards. We should not decide the inherited characteristics of future generations which imposes these down-sides on them without their consent.*
> Australian male non-parent, 65+, postgraduate, genetic condition in family, not genetically tested

Slippery slopes

Concerns were also raised about the potential for this use of the procedure to give rise to a 'slippery slope' towards other kinds of use, which it was implied would not be ethically acceptable.

> *Once the creation of GM babies for relatively minor impairments such as this was permitted, experience with drugs and surgery shows that it will be impossible to prevent the use of the technology to create 'enhanced' designer babies. Such a future of consumer eugenics would be socially disastrous, creating a society in which people are valued according to their genes.*
> British male non-parent, 55-65, postgraduate, genetic condition in family, genetically tested

> *Though this would be a 'therapeutic' application, the incremental extension to 'enhancement' techniques in inevitable once this line is crossed.*
> British male parent, 65+, postgraduate, genetic condition in family, not genetically tested

Availability of alternative options

Respondents also suggested other treatments and approaches that might be employed instead of using the technique described in the scenario.

> *There are already treatments that exist to help this. We shouldn't be looking for seemingly "quick, easy, cheap" fixes within the genome. They're messaged as "quick easy and cheap" but that doesn't seem to be the case. This is not normal and we should NOT perpetuate the idea that editing out genes is okay."*
> Filipino female non-parent, 25-34, graduate, genetic condition in family, not genetically tested

> *… Ruling out procreation between some individuals on the basis of genetic analysis of deleterious genetic information, as some communities are now doing, is an ethical and rational intervention.*
> Australian male non-parent, 65+, postgraduate, genetic condition in family, not genetically tested

Consent

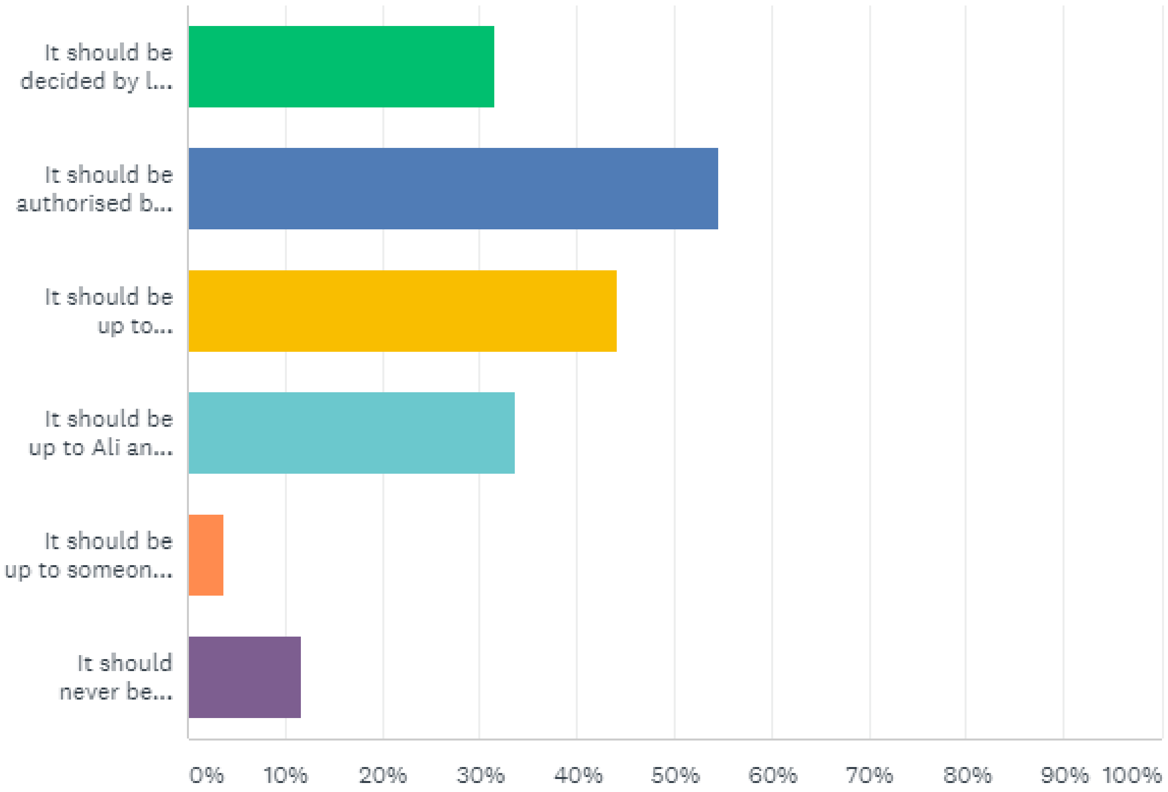
The issue of consent was also raised by a further respondent:

> *… None of the future descendants can give you permission to do this.*
> *British male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

> *Issues of consent and safety, as above.*
> *British male parent, 65+, postgraduate, genetic condition in family, not genetically tested*

Question 3

Whose authorisation should be required before Ali and Brian can have access to this treatment?



It should be decided by laws made by Parliament
100 of 317 respondents (32%)

It should be authorised by a regulatory body that takes both expert advice on safety and public opinion about acceptability into account
173 of 317 respondents (55%)

It should be up to scientists and doctors to decide that it is safe enough and appropriate for Ali and Brian to go ahead
140 of 317 respondents (44%)

It should be up to Ali and Brian alone to decide whether they have the treatment
107 of 317 respondents (34%)

It should be up to someone else
12 of 317 respondents (4%)

It should never be allowed
37 of 317 respondents (12%)

Respondents who answered, ‘It should be decided by laws made by Parliament’

The involvement of Parliament would give society a say

A number of respondents said that involving Parliament would mean that members of the public would have a role in decision making on use of the procedure.

> *It is important that as a society we note and accept the risks of deliberate genetic modification being passed on, which is why I would want it to be debated in Parliament. However I think that Parliament should bow to the advice of professionals when ultimately deciding the availability of the treatment.*
> *British female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *There needs to be open public consultation about this. There is a need for balancing here too and a precautionary principle approach may be needed.*
> *British female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *Germline gene editing will affect the manner in which the whole of society consider the value and worth of human life. As a result any decision relating to the value and worth of a life should be made in parliament.*
> *British male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

> *Some people will have concerns, and the proper place to discuss these, and for decisions to be made, is Parliament*.
> *American female non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

The decision of Parliament would be impartial

Some respondents said that those directly involved, such as scientists, medical professionals or people in the position of Ali and Brian themselves, would find it difficult to make objective decisions about such matters. Parliament, which is able to take a balanced view of all considerations would be in a better position to do this, some thought.

> *Scientists and physicians, and the affected individuals, do not have the objectivity to make rational decisions about the future of humanity. Laws must be informed by impartial regulatory bodies that must be able to take opposing feedback into equal consideration without imbalanced consideration of particular views that are fuelled by greater resources (eg: fertility-business corporations).*
> *American male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *It is better to have the state decide the perimeters of the laws, with the objective opinion of medical experts determining on a case by case scenario. It should never be just down to the couple as their opinion is subjective.*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

The appearance of impartiality was also cited as important by one respondent

> *This sort of research and activity need to be strictly regulated so that unwanted genomic changes are not introduced into the human germ line. And so that regulation is seen to be impartial.*
> *British female parent, 65+, graduate, no genetic condition in family, not genetically tested*

Need for legal framework and protections to assure safety

The importance of appropriate legislation governing use of the procedure was emphasised by a number respondents. This was important both to protect those involved and the enable monitoring of such practices.

> *As with all procedures of this kind, there must be legislation in place to protect those undergoing it and to maintain safety standards*
> *French female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *There should be checks and balances.*
> *British female parent, 55-64, college educated, no genetic condition in family, not genetically tested*

Some clarified that legislation would be one of a number of measures that would be necessary to ensure that provision of the procedure was delivered safely and appropriately.

> *Having a statutory framework would provide structure, a multidisciplinary team would provide a balance of views and expertise, and an external reviewer or external body with oversight would provide the safeguarding aspect.*
> *British female parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

Final decision should be for Brian and Ali

Some respondents emphasised that, however decisions about availability were made, it was important that Ali and Brian themselves should have the responsibility and power to make their own personal decision about whether to actually make use of the procedure.

> *The law should permit the procedure based on information from scientists and doctors regarding its feasibility and potential risks/rewards. Brian and Ali should then have the final decision on whether to go ahead.*
> *British male non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *We should have laws about cases like this, and an ethical committee of professionals from different disciplines should be in it. And of course Ali and Brian are the ones who decide if they really want to have the procedure, after the parliament and the regulatory body have decided that it is allowed.*
> *Dutch female non-parent, 18-24, postgraduate, genetic condition in family, not genetically tested*

> *In an ideal world these Laws and Regulatory bodies would ensure that only treatments considered safe and ethical are available to Ali and Brian however the decision should ultimately be in their hands.*
> *Scottish female non-parent, 18-24, college educated, no genetic condition in family, not genetically tested*

Ethics committees should be involved

Some respondents said that the use of ethics committees would be useful in determining where use of the procedure would be appropriate.

> *The decision would be made by an Ethics Committee, with reference to the legal system, I think.*
> *Demographic data not provided*

> *Strong ethics committee involvement as well.*

> British male non-parent, 18-24, college educated, no genetic condition in family, has had genetic test

Respondents who answered ‘It should be authorised by a regulatory body that takes both expert advice on safety and public opinion about acceptability into account’

Case-by-case decision making

Some respondents thought that involvement of a regulatory body would be appropriate insofar as it would be empowered to make individual decisions, on a case-by-case basis.

> *…Such a regulatory body would…be in a position to make acceptable decisions, on a case-by-case basis.*
> *Demographic data not provided*

> *It is better to have the state decide the perimeters of the laws, with the objective opinion of medical experts determining on a case by case scenario. It should never be just down to the couple as their opinion is subjective.*
> *British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

Sensitivity to expert advice

A number of those responding this way mentioned the importance of making use of relevant expertise, medical or scientific, in decisions about availability of the procedure.

> *I believe that the regulatory body should be the driving force in consulting public opinion and expert advice, and weighing between the two to arrive at a decision. …*
> *Singaporean female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *It needs doctors and scientists to determine if appropriate to Ali & Brian's particular case. It needs an independent body, taking expert advice into consideration, to authorise the techniques in principle. I think that authorisation should be based on science (not religious beliefs).*
> *British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

A regulator would have powers to monitor practice and enforce standards

Some raised the importance of monitoring the use of the procedure, were it to be allowed.

> *This is neither only a technical or scientific matter, not only an individual decision. The deployment of new technologies (and arguably all new technologies not just reproductive or biomedical technologies) should operate through socially robust and inclusive mechanisms that allow for on-going monitoring and flexible adaptation.*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

> *Need long term follow up*
> *British female parent, 55-64, postgraduate, genetic condition in family, has had genetic test*

A related point concerned the enforcement of clinical standards for the purposes of safety.

> *As with all procedures of this kind, there must be legislation in place to protect those undergoing it and to maintain safety standards*
> *French female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

A regulator would be impartial

The importance of avoiding partiality and bias in decision making was raised.

> *Scientists and physicians, and the affected individuals, do not have the objectivity to make rational decisions about the future of humanity. Laws must be informed by impartial regulatory bodies, that must be able to take opposing feedback into equal consideration without imbalanced consideration of particular views that are fuelled by greater resources (eg: fertility-business corporations).*
> *American male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *The body will be unbiased and take a variety of views and arguments into account*
> *British female non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested*

Risk of open market in genome editing procedures

Some comments reflected the idea that there should not be entirely unrestricted use of the procedure, for less well-founded medical reasons than Ali's and Brian's.

> *We don't want a market in unscrupulous medical procedures.*
> *New Zealand male parent, 65+, postgraduate, genetic condition in family, has had genetic test*

One respondent singled out cosmetic uses of the techniques as examples that regulation should rule out.

> *There should be some regulation so that people aren't using this technique for cosmetic (e.g. wanting a child with certain looks) purposes*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

Religious and cultural groups should be consulted by a regulatory body

Some felt that it was important to involve religious groups or those with particular cultural interests in the process that preceded the decision on whether this should happen or not.

> *…I ticked the option "it should be up to someone else" because I felt that the regulatory body should also consult religious leaders and international experts / opinion (scientists, ECHR leaders, UNESCO leaders in bioethics), in arriving at this decision. The decision to authorise germline editing should be an international responsibility, not just a national one. i.e. say if the BRITISH is the first country in the world to legalise this technology, other countries will quickly follow suit. So the international impact of the decision will have to be taken into account. Ultimately, Parliament should be the final arbiter of the legality of treatment.*
> *Singapore female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *Public input should include cultural, ethical, and moral considerations as well a systematic attempt to offer the public's representatives understanding of the scientific (clinical, epidemiological, and ecological) issues.*
> *Canadian parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

Ethics committees should be involved

Ethics committees were mentioned.

> *An Ethics Committee, with reference to the legal system, would make the decision I think.*
> Demographic data not provided

> *Strong ethics committee involvement as well*
> British male non-parent, 18-24, college educated, no genetic condition in family, has had genetic test

Need for guidance

Some felt that it would be important for a regulatory body to draft guidance on use of the procedure before it was made available to patients.

> *I ultimately think that the couple should have the final say in what they want to happen, but I also think that there should be further study on the outcomes of the procedure. Some type of regulatory body should create guidelines before allowing the procedure.*
> American male parent, 25-34, postgraduate, genetic condition in family, has had genetic test

One respondent said that this guidance should include advice on what conditions could be treated with the procedure.

> *As I understand it, the current technique is not permitted by BRITISH law, and therefore changes in the law would be absolutely necessary. As with mitochondrial replacement, should the technique become legal, I believe it should become a licensable procedure, subject to HFEA approval. The HFEA should produce guidelines on which conditions genome editing may be considered as a treatment, although each application for the use of genome editing should be considered individually, and the presence of a condition on any list or guidelines should be no guarantee of a licence being granted. At the clinic level, any 'offer' of genome editing as a treatment option should be at the discretion of the clinicians, with the consent of the patients, and in the knowledge that an application for a licence to use genome editing may not be successful.*
> British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

Respondents who answered, ‘It should be up to scientists and doctors to decide that it is safe enough and appropriate for Ali and Brian to go ahead’

Experts can ensure a decision is informed by evidence on safety and efficacy

Some felt that doctors and scientists were in the best position to appraise evidence on the safety of the procedure.

> *There should be medical and scientific oversight regarding the safety and efficiency of the procedure. But so long as there is some credible evidence of its efficiency and low-risk, it's the patients who have to decide.*
> British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

> *…I think that this procedure is in-principle permissible. I selected the answers that I did because I do believe that regulatory bodies with the time and dedication to evaluate expert advice on safety should be involved in the implementation of novel tech. I also believe that it is scientists and doctors who should be primarily involved in judgments of safety. That said, judgments of safety are actually not value-free.*

> *They always turn on some pre-existing notion of which risks are allowable, and which are not….*
> American female parent, 35-44, postgraduate, genetic condition in family, not genetically tested

One respondent explicitly contrasted this with option with enabling a regulator to take decisions on use of the procedure which, they said, might be unduly influenced by public opinion. This might not match up with what evidence indicates about proper use of the procedure.

> *I would have ticked the second box - I prefer a regulatory body approach - but was concerned too much emphasis might be placed on public opinion rather than evidence.*
> British male non-parent, 56-64, graduate, no genetic condition in family, not genetically tested

Case by case decision making

Some said that the judgement of clinicians and scientists would be needed in particular cases about whether a given couple were good candidates for the procedure.

> *It needs doctors and scientists to determine if appropriate to Ali & Brian's particular case. It needs an independent body, taking expert advice into consideration, to authorise the techniques in principle. I think that authorisation should be based on science (not religious beliefs).*
> British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested

> *…At the clinic level, any 'offer' of genome editing as a treatment option should be at the discretion of the clinicians, with the consent of the patients, and in the knowledge that an application for a licence to use genome editing may not be successful.*
> British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

One respondent specified that other than Ali and Brian, no individuals, groups or bodies other than doctors and scientists should have any say in whether Ali and Brian should be able to use the procedure.

> *It is their decision to have the treatment; and it is the decision of doctors and scientists as to whether they want to offer the treatment. I see no right for others to interfere in those decisions.*
> American male non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested

Experts other than doctors and scientists should also be involved

It was said by one respondent that expertise in this area extended beyond science and medicine and that professionals involved in social justice should also be involved in decision making.

> *I think we also need to define the word expert and what does that mean. Many folks that work in the social justice atmosphere who represent people who could simultaneously be both most and least impacted by new procedures like Ali and Brian should be in the space in which we decided how and in what circumstance genome and/or somatic editing should take place.*
> American female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

Respondents who answered ‘It should be up to someone else’

Ethics committee

One respondent said that an ethics committee should make the decision, working within a legal framework.

> *The decision would be made by an Ethics Committee, with reference to the legal system…*
> *Demographic data not provided*

Spokesperson for the future child

A representative for the child to be born should be involved, one respondent said:

> *There should be a spokesperson for the child to be that tells the parents to be about its concerns*
> *German female non-parent, 18-24, college educated, genetic condition in family, not genetically tested*

A new body

One respondent suggested that a new organisation not bound by existing legislative and regulatory frameworks should be constructed to address such questions

> *None of these options correspond with my views as all but the last option rely on existing governance structures. Maybe we need something new... (not someone else... but that is what I selected given the options)*
> *Canadian female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

Respondents who answered ‘It should be up to Ali and Brian alone to decide whether they have the treatment’

Ali and Brian are entitled to make their own decisions

A number of respondents said that that no one else should be involved in these decisions and Ali and Brian should be allowed to make up their own mind about whether to use it, citing concepts like privacy, self-determination, choice and freedom as relevant.

> *It is no one else's business (except the child, who cannot at the time the decision must be taken express an opinion).*
> *British male parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

> *Privacy, personal self-determination, bureaucracy is horrible, regulatory capture, etc.*
> *American female non-parent, 35-44, postgraduate, genetic condition in family, has had genetic test*

> *It is their life and child, why must anyone else need to interfere?*
> *British female non-parent, 25-34, graduate, genetic condition in family, has had genetic test*

> *Their bodies, their choice.*
> *American male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Ali and Brian are best placed to make the right decision

Some respondents suggested that given Ali and Brian’s insight into their own circumstances, they were the people most likely to come to the right decision about whether the procedure should be used.

> *Two people know what is best for their offspring*
> *British female parent, 35-44, graduate, no genetic condition in family, has had genetic test*

> *The people involved should decide*
> *American male parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Ali and Brian are entitled to make their own decisions with the support of medical professionals

Some added a caveat that expert medical opinion was also important and that Ali and Brian’s decision should be made with the support of doctors and scientists.

> *It is their decision to have the treatment; and it is the decision of doctors and scientists as to whether they want to offer the treatment. I see no right for others to interfere in those decisions.*
> *American male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

> *Medical decisions need to remain between doctors and their patients.*
> *American female non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

The procedure must be safe

One respondent suggested that Ali and Brian should be able to make their own decision about whether to use the procedure as long as it is safe

> *I can't see any legal reasons why it shouldn't be allowed. Safety is the primary concern.*
> *British male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Respondents who answered ‘It should never be allowed’

Availability of alternative options

Some respondents pointed out that there were other ways for Ali and Brian to have a child and therefore did not need to use the procedure to become parents. Adoption and gamete donation were posed as possible alternatives

> *They can adopt a child to fulfil their longing for a family. Or get a sperm donation from someone who hasn't*
> *Australian female non-parent, 45-54, postgraduate, genetic condition in family, has had genetic test*

And another mentioned PGD, suggesting that this raised questions about the need for this technology.

> *Where is discussion or inquiry into questioning the need for this technology to prevent the transmission of serious inherited disease, given other options such as PGD available?*

> American female parent, 55-64, postgraduate, genetic condition in family, has had genetic test

Uncertainty about long term consequences

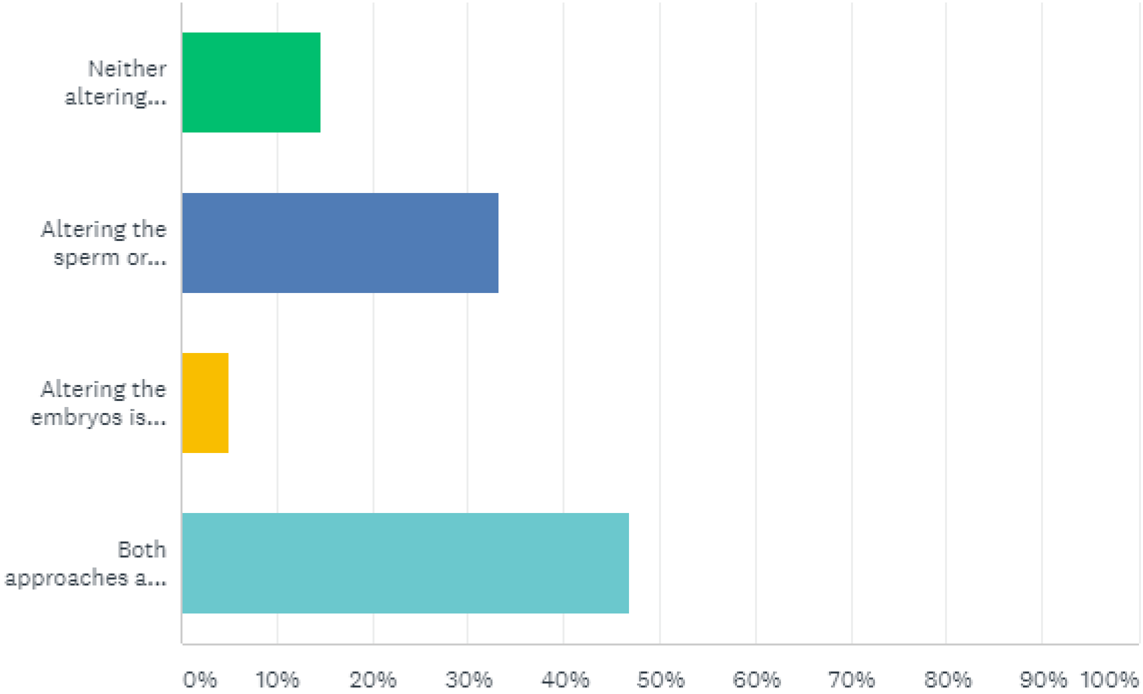
Some respondents were concerned about the use of such techniques given the difficulty of ensuring with full certainty that they are safe.

> *Editing all forms of germ line cells carries an unquantifiable risk, lacks compelling medical evidence base at this stage, and is ethically unacceptable on these and on the consent issue mentioned above*
> *British male parent, 65+, postgraduate, genetic condition in family, not genetically tested*

> *Germline cells should not be tampered with... not until there is MORE than sufficient evidence. In many times in history there have been too good to be true technologies. One caused Chernobyl, Hiroshima, Nagasaki, Fushima, Long Island... Just because we can, does not mean we should....*
> *British male parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

Question 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
46 of 313 respondents (15%)

Altering the sperm or tissues that produce sperm is preferable to altering the embryos
104 of 313 respondents (33%)

Altering the embryos is preferable to altering the sperm or tissues that produce sperm
16 of 313 respondents (5%)

Both approaches are equally acceptable
147 of 313 respondents (47%)

Respondents who answered ‘Neither altering embryos nor altering sperm is acceptable’

Uncertainty about long term consequences

Some respondents were concerned about the extent of our understanding of the possible effects of using genome editing technologies to alter embryos or sperm, suggesting that we do not know enough about the consequences of doing this.

> *The long term consequences of such technology is unknown.*
> *Australian female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *Insufficient knowledge available*
> *British male parent, 65+, postgraduate, no genetic condition in family, genetically tested*

> *For me the risk is in the alteration of any material.*
> *American male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Concerns about societal impacts

Some respondents raised concerns about the potential implications for wider society, rather than the effects on Brian or a future child, of use of such techniques.

> *The arguments against the creation of GM babies and consumer eugenics do not depend upon whether sperm or embryos are genetically engineered. It is not about the putative 'sanctity' of the embryo, but about the social consequences.*
> *British male parent, 55-64, postgraduate, genetic condition in family, genetically tested*

One respondent suggested that the use of the technique would lead to eugenics and said that use of such techniques would ultimately result in the development of a new, post-human species.

> *Neither are acceptable because both mark the advent of a new techno-eugenics that would set us on the road towards division of the human community into genetic castes - the "gene-rich" and the "gene-poor" - and eventually to human speciation.*
> *American male non-parent, 65+, postgraduate, genetic condition in family, not genetically tested*

Use of either procedure would lead to non-medical uses of the technique

Another concern raised was that this use of the procedure would lead to a wider range of non-medical uses of the technique, that it was suggested would be wrong

> *In this case the procedure is not a medical necessity so should not be allowed given that it opens the door further toward "designer" procedures, which are also not medical necessities.*
> *Canadian male non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

Those who responded ‘Altering the sperm or tissues that produce sperm is preferable to altering the embryos’

Brian would be able to consent to the procedure

A number of respondents raised the issue of consent and suggested that since Brian, but not the future person, would be able to consent to undergoing a procedure, it would be preferable to conduct the procedure on Brian

> *The father would have a choice, the embryo would not*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*
>
> *An adult can give informed consent whereas altering an embryo is a much more contentious issue.*
> *British female parent, 55-64, graduate, genetic condition in family, genetically tested*

Though one respondent acknowledged the metaphysical difficulties associated with this line of thought.

> *I feel that altering the sperm as a tissue of Brians own body is something he has more authority over, if the procedure didn't work presumably fertilisation wouldn't work. Intervening after fertilisation with a developing embryo is slightly different in my mind. However even if the subsequent procedure damaged the embryo we are saying that actually without the procedure the embryo wouldn't develop anyway so perhaps the risk of the procedure to the embryo cant be taken into account. British Female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Altering sperm or tissue would resemble fertility treatment for Brian

Some respondents thought that altering sperm or tissue was closer to a conventional fertility treatment, and preferable to modifying an embryo for that reason.

> *It would mean we have solved Brian's problem rather than artificially triggering the development of an embryo.*
> *Italian male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*
>
> *…It might be possible for a natural law perspective to see this as a reparative treatment, in other words as a therapy. One is here trying to restore function to a damaged organ or tissue rather than trying to alter a human organism (the embryo). For these reasons at least, altering spermatogenic tissues would be preferable to altering embryos.*
> *American female parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

One respondent said that this was partly because of the way that conceptualising the procedure as a fertility treatment could help to constrain other the uses of the techniques, some of which it was suggested would not be acceptable.

> *I am prepared to say that genetic editing is permissible when it is targeted at fertility disorders in the couple, but not permissible when it is targeted at fixing genetic diseases in embryos more generally. The former has a defined and limited scope, whilst the latter is theoretically limitless (i.e. is a genetic disease a disease because it causes suffering, or because healthy individuals harbour prejudices towards it?). Altering the mutation in Brian's sperm would help to distinguish the treatment from more a more general alteration of the resulting embryo's characteristics.*
> *Singaporean female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

Altering sperm or tissue would be safer

Safety was raised as an important consideration

> *It really depends on the procedure itself right what is safer and less invasive. It seems like the sperm/tissues that produce sperm is the best bet.*
> *American female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*
>
> *Potential safety concerns regarding altering embryos.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

One respondent said that altering sperm carried less risk of mosaicism in the future child.

> *Sperm alteration seems safer since you won't be worried about mosaicism in the child*
> *Demographic data not provided*

Another respondent said that this option would be safer since complications undertaking the procedure might mean that fertilisation would simply fail whereas, it was suggested, problems with altering the embryo could result in the birth of a child that might have been adversely affected by the procedure

> *Less likely to have other complications in the embryo, if there was a problem with the sperm the egg likely won't be fertilised successfully*
> *British female non-parent, 0-17, Seconday school educated, no genetic condition in family, not genetically tested*

Altering sperm would be more straightforward

Some thought that altering sperm, specifically, would be the procedure most likely to of the three to be effective because sperm are simpler entities than embryos.

> *DNA in sperm is haploid... a single cell... and there is one copy. Embryos have many cells. IF CRISPR tech was to be allowed, which it should not be until there is ample evidence.. then it should only be allowed on a single cell - gamete - PRE-fertilisation - before other more subtle genetic events occur that science is only just discovering, and most people know nothing about....*
> *British male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*
>
> *Sperm are a simpler one-parent only tissue - better to modify "component" rather than final product of conception with gametes from 2 parents*
> *British male parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*
>
> *I think it might be simpler to do this but I am unsure because I do not know how much this would affect Brian.*
> *British female parent, 55-64, postgraduate, genetic condition in family, genetically tested*

Broader solution to Brian’s fertility issues

Some respondents thought that altering Brian’s tissue would enable him and Ali to have more healthy children without further assistance

> *Both approaches could be acceptable so long as there is no major foreseeable harm. Alteration to Brian's spermatogenic tissue could introduce some risk for a resulting foetus as much as embryo alteration could. It is somewhat more likely to involve some possible harm to Brian. This would be quite unusual in terms of*

> *assisted reproductive tech, most of which is done with and on women's tissues or bodies. However, if Brian were to be able to choose to attempt to alter his spermatogenic tissues or his sperm, I can see why this might be preferred for several reasons. First, if it alters his spermatogenic tissues, he will then be able to try to conceive many times without needing further treatment, and without generating more embryos. Second, to do the procedure on the embryos requires inducing egg-production and harvesting eggs from Ali, which has long-term health risks and is quite uncomfortable. It is also much more expensive.*
> *American female parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

> *Is better because Brian could have other children without these fertility problems.*
> *Spanish female non-parent, 18-24, graduate, no genetic condition in family, genetically tested*

> *Cheaper, possibility of having more children.*
> *Spanish male non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

Altering Brian's tissue might be more morally acceptable to some

One point made was that altering tissue might be seen as less ethically problematic for some people, given the special status that embryos have in the views of some.

> *Removing the problem before it even becomes an embryo would be ideal. Less interference in the long term. The parents can have more children. It may be easier to accept for people who are opposed to interfering with embryos.*
> *British male parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *At this stage of knowledge, altering sperm or ovum will enable nature to compensate for mistakes, and remove pressure which may be brought by devout religious groups who object to changes being made to embryos.*
> *British female parent, 65+, graduate, no genetic condition in family, not genetically tested*

> *Further away from the development of a human being the more likely it is to be socially acceptable*
> *Scottish female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *This is an interesting question. For some people, the human embryo is a person. I am not one of those people, but I do agree with the special status granted to the human embryo, and I agree with measures and good practice guidelines which limit unnecessary production of human embryos.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

More information needed

One respondent suggested that more information was required in order to make a judgement about the case

> *The question is generally too vague; technical feasibility etc. are essential to answer this.*
> *German male parent, 45-54, doctorate, no genetic condition in family, genetically tested*

Respondents who answered ‘Altering the embryos is preferable to altering the sperm or tissues that produce sperm’

Lower risk of harm

Some respondents thought that it would be safer to modify an entity outside the body and that altering Brian’s cells instead would carry risks to an existing person

> *Altering the embryos is better as the knock-on effects in the body could be more complex whereas an embryo not developing is not harmful. If the sperm could be altered outside of the body this could be okay too.*
> *French female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *If problems arise from the intervention you will lose only an embryo that would not survive anyway. Cancer is a greater risk for genetic alteration in Brian. Not to mention how difficult it might be, as we are talking about gene therapy here!*
> *Greek female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

It was also suggested that if there were problems with the altered sperm this could result in the birth of more than one affected child.

> *Altering embryos is more contained, if the man sleeps around after his tissues are altered there may be unforeseen consequences for accidental conceptions*
> *British female non-parent, 18-24, college educated, genetic condition in family, not genetically tested*

It was also pointed out that Brian would be the only patient, legally.

> *Altering the embryo has lower risk for the parent, who currently has primacy in law. Should the alteration have deleterious effects, these would carry potentially greater and less remediable harm to the parent if their germ cells or related tissues are altered, compared with the embryo.*
> *Demographic data not provided*

Altering the embryos would be more likely to work

Some respondents suggested that altering the embryo would be more likely to be successful, since the changes could be more directly targeted.

> *There may be no way of selecting the sperm with the altered characteristics, whereas in case of embryos, the correctly altered ones will develop. This applies to the altering of Brian's tissues in vivo: there is no guarantee that the sperm-producing tissues will be altered, and there may not be away of selecting the sperm with required characteristics.*
> *Russian female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *Altering the embryo is a more specific and targeted intervention compared to tissues that produce sperm, which is potentially more efficient. I personally do not have a moral objection to altering embryos compared to sperm, if the intervention to alter sperm turned out to be more efficacious I would choose that.*
> *Canadian female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Respondents who answered ‘Both approaches are equally acceptable’

Whichever procedure is the most safest and effective should be used

Some respondents said that the most important considerations were the relative safety and efficacy of each technique.

> *Use the process that has the best chance of success with minimal damage the (future) embryo*
> *British female non-parent, 18-24, college educated, no genetic condition in family, not genetically tested*

> *Safety and efficacy more important than locus*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

> *The choice should be on the safest and more effective option, I don't see any difference in altering the genome using the sperm or the embryo.*
> *Italian female non-parent, 35-44, postgraduate, no genetic condition in family, genetically tested*

A further consideration listed amongst these factors was the financial implications of each option.

> *It only depends on costs, safety, etc. I cannot come out with any morally relevant difference between interventions before and interventions after conception.*
> *Italian male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Neither tissue, sperm nor embryos have special moral status

Some respondents expressed their views in terms of their opinions on the status of tissue, gametes and embryos, suggesting that altering these entities did not necessarily raise any special ethical questions

> *Neither individual tissues nor embryos are morally significant on their own. This is an implementation detail that may effect efficacy, safety, etc., but it does not effect morality.*
> *American male non-parent, 25-34, postgraduate, genetic condition in family, genetically tested*

> *I personally do not think embryos are particularly special, and different from other human tissues at an early stage.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *Gametes aren't magic*
> *American male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Altering sperm might be preferable overall

Some answering this way nevertheless entertained the idea that editing sperm might be preferable in some ways to editing embryos. One respondent said that modifying Brian’s sperm made the procedure more like a treatment to aid Brian’s fertility rather than a modification on what would become a person

> *Altering Brian's sperm or tissues would allow for a solution that would remove his condition for any future offspring, which is a benefit to the extent that this is a safe thing to do. Where there are concerns about unintended consequences, the permanence of this solution might make it a worse option that altering embryos.*

> *There is something more natural-seeming about doing this procedure on Brian (although this may be a perception only), as it seems more like a treatment for his condition rather than an altering of a future person.*
> *British female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

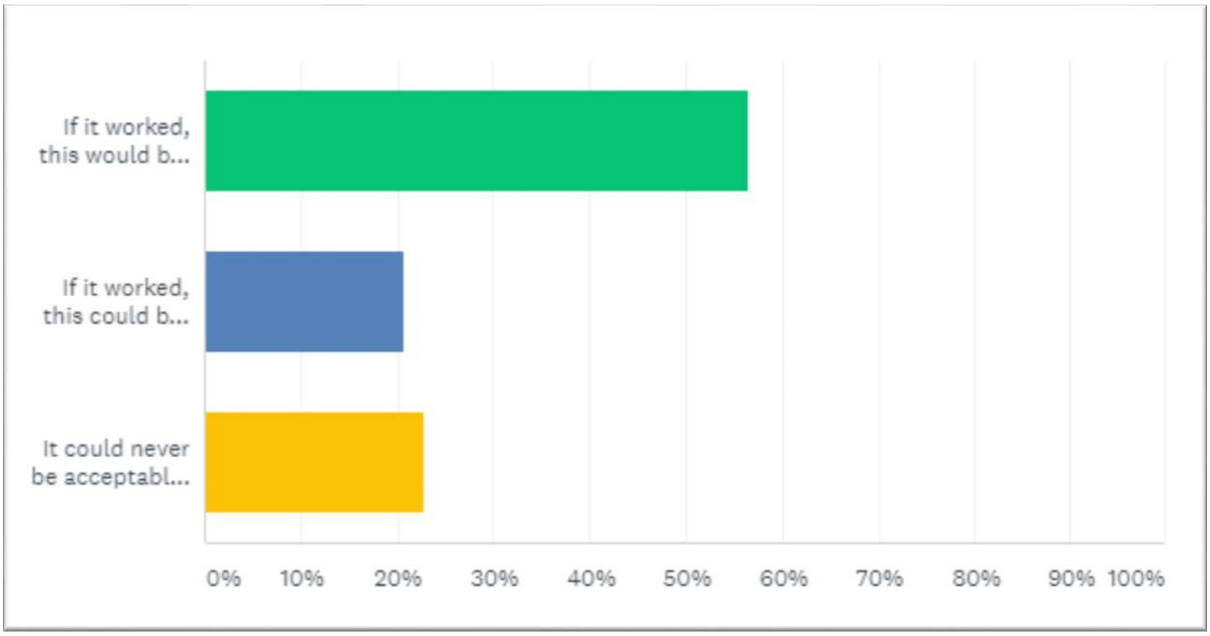
> *If the procedure itself (rather than the genetic alterations) carries a risk of destroying or damaging the cells used, it would be preferable to do this in sperm. It may be less risky to alter the sperm than the tissues which produce sperm, since if there is a problem with the procedure it can be repeated with fresh sperm, whereas negative consequences of altering sperm-producing tissues could be more permanent.*
> *Demographic data not provided*

Another point raised in support of altering Brian's sperm rather than the embryo was that it would mean that he would experience the benefits if he had further children.

> *If the risk is the same there is no difference; though doing it to the sperm would have the advantage that Brian could have children with anyone in the future and not just be limited to a single incidence.*
> *British male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Question 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
175 of 310 respondents (56%)

If it worked, this could be acceptable under certain circumstances (please tell us what these should be)
64 of 310 respondents (20%)

It could never be acceptable to produce children using cells other than reproductive cells (eggs and sperm)
71 of 310 respondents (23%)

Respondents who answered 'If it worked, this would be an acceptable alternative'

If the procedure is safe and produces a healthy child

A number of respondents said that as long as altering laboratory grown stem cells was safe it would be acceptable to use a procedure based on this technique:

> *As long as the resultant child's health was not affected by this, I don't personally feel that it would be especially relevant how the child had been produced. One concern is that the child could face some stigma/negative social responses as a result.*
> *British, female non-parent, 18-24, postgraduate, genetically tested, has genetic condition in family*

> *Again, if it makes no difference to the couple nor the offspring, then it's only a matter of safety and simplicity of the method (assuming it's equally efficacious).*
> *Demographic data not provided*

A variation on this point was that editing should be done on Brian's stem cells only if this was the safest and most effective version of the procedure.

> *Again, the choice should be on the safest and more effective option.*
> *Italian, female non-parent, 35-44, postgraduate, genetically tested, has genetic condition in family*

> *Choose the alternative most likely to succeed*
> *British, male parent, 65+, postgraduate, genetically tested, has genetic condition in family*

The situation is morally equivalent to altering Brian's sperm

A number of respondents said that this variation on the procedure did not present any distinctive ethical issues.

> *It's no different really.*
> *British, male non-parent, 25-34, graduateelors, genetically tested, has genetic condition in family*

> *Once the procedure is accepted in principle, the process is ok.*
> *British, male non-parent, 35-44, graduateelors, genetically tested, has genetic condition in family*

> *Again, if this produces the same outcome then to me it is morally equivalent to the first options….*
> *British, female non-parent, 18-24, graduate, genetically tested, has genetic condition in family*

Reproductive cells and embryos are not special

Some respondents made related points about the status of reproductive cells or embryos in contrast with stem cells. They expressed views that these entities have no intrinsic moral value, suggesting that use of stem cells, as opposed to reproductive cells, would not clearly make things morally more or less problematic.

> *Again, this seems identical to me, all else being equal. There is nothing particularly magical about sperm.*
> *American, male non-parent, 45-54, postgraduate, genetically tested, has genetic condition in family*

> *I don't see sperm/eggs or embryos as having a special moral status.*

> Canadian, female non-parent, 25-34, postgraduate, genetically tested, has genetic condition in family

One respondent expressed this view as scepticism about the sanctity of these cells and stated that views about the sacred nature of such materials should not influence the decisions made about the use of such techniques.

> *The only distinction I can imagine here is one based on sacredness (purity/pollution), which should not inform multicultural debates in civil society.*
> American, female non-parent, 35-44, postgraduate, genetically tested, has genetic condition in family

Slippery slopes

One respondent was concerned that use of this procedure might initiate a slippery slope, suggesting concern about the expansion of applications of such techniques into areas less worthy of intervention.

> *Great for this purpose if possible although safeguarding against slippery slope to be considered.*
> Demographic data not provided

Respondents who answered 'If it worked, this could be acceptable under certain circumstances (please tell us what these should be)

If the procedure was safe or safer than alternatives

Some respondents who answered this way stressed the importance of the safety of whichever technique was used, stating that if this approach was as safe as, or safer than, the alternative methods then it would be acceptable.

> *As long as the safety of the technique is the same as that altering the reproductive cells.*
> Italian, female non-parent, 25-34, graduate, genetically tested, has genetic condition in family

> *If this method significantly reduced the risk compared to altering Brian's tissue or if there was another issue that prevented Brian from having children the natural way.*
> British, female non-parent, 25-34, postgraduate, genetically tested, has genetic condition in family

> *If this would be a safer alternative or elsewise medically preferable.*
> British, does not identify as male/female, non-parent, 18-24, College, genetically tested, has genetic condition in family

If alternative routes to genetic parenthood would not work for Ali and Brian

Some respondents suggested that use of such a technique would be problematic, but expressed the view that if there were no alternative options for Ali and Brian to have genetically related children, it might be acceptable.

> *Something about this makes me feel quite uneasy... but if there was no other way for this couple to produce biological offspring I could be convinced.*
> American, female non-parent, 25-34, postgraduate, genetically tested, has genetic condition in family

One respondent answering this way made clear that they thought there would be risks involved in use of this procedure and that it should only be used once other approaches had failed

> *I think this should be a last resort, it seems being external to a human that more could go wrong.*
> *British, female parent, 18-24, graduate, genetically tested, has genetic condition in family*

If the public had been consulted on use of the procedure

Another line of argument expressed was that the wider public should be involved in decisions about the use of these procedures and that their use would not be acceptable unless the ethical aspects of their uses had been discussed in public consultation.

> *Scientific technique will disclose efficacy, but the ethical, legal, and social implications of such scientific procedures need further public discussion and development in policy before such actions should be permitted.*
> *American, male parent, 55-64, postgraduate, genetically tested, has genetic condition in family*

Another respondent said that decisions about the use of such procedures should be accountable to the public

> *Again the two criterion a) that policy is democratic and accountable to the public and made available to all irrespective of their economic capacity to pay for it and b) a very small number of applications of gene therapy are trialled until we have concrete evidence that this would not result in other abnormalities in descendants.*
> *British, male non-parent, 25-34, postgraduate, genetically tested, has genetic condition in family*

If appropriate legal protections were in place

A related point made by some that it would be important for the appropriate legal and regulatory constraints to be in place before such a procedure was used.

> *Given the abovementioned circumstances, I would rather do it this way to be perfectly honest. With clear framework of law of course.*
> *Greek, female non-parent, 25-34, postgraduate, genetically tested, has genetic condition in family*
>
> *Would need careful regulation by laws of parliament*
> *English female non-parent, 25-34, postgraduate, genetically tested, has genetic condition in family*

A combination of circumstances would be relevant

Some respondents cited a number of different factors and describe a range of conditions on which the acceptability of the procedure would depend.

> *If the procedure was safe, the only way (editing sperm/tissues producing sperm would be preferable), and no other genetic changes had to be made besides the proposed change*
> *British, female non-parent, 0-17, Secondary school, genetically tested, has genetic condition in family*
>
> *These should include factors such as risk to Brian's health and to the embryo created from this procedure, cost and to what extent this process might have other benefits in advancing genome therapy for other conditions.*
> *British, female parent, 55-64, graduate, genetically tested, has genetic condition in family*

Opportunity costs

One respondent pointed out that use of such a procedure might be expensive and suggested that this raised questions about whether this money could be put to better use in other health contexts.

> *Again, this would seem reasonable if the level of certainty around safety concerning the procedure and the consequences for future generations is established. There is another question, though, about equity and how much this would cost. If it were going to be very expensive, then the money would be better off used to improve health in low and middle income countries.*
> *British male parent, 55-64, postgraduate, genetically tested, has genetic condition in family*

Respondents who answered ‘It could never be acceptable to produce children using cells other than reproductive cells (eggs and sperm)’

Safety and uncertainty about long-term consequences

Some of those that said that use of cells other than reproductive cells to produce children could never be acceptable were concerned about the safety of such techniques, particularly given our incomplete knowledge of the effects such procedures.

> *Insufficient knowledge available*
> *British male parent, 65+, postgraduate, genetically tested, has genetic condition in family*

> *See above comment regarding safety,*
> *American female parent, 55-64, doctorate, has genetic condition in family, genetically tested*

> *Again this is simplistic. Where is the evidence regarding risks? How can one possibly answer (or for that matter research) such important questions without solid evidence regarding what is actually possible, what the long term consequences-including intergenerational consequences-will/may be, what the actual risks are, what is unknown....*
> *British male non-parent, 18-24, college educated, genetically tested, has genetic condition in family*

One of those who expressed this view suggested that it would be very difficult to ever gather sufficient evidence to be confident of the effects of use of such procedures.

> *Again, "never" is a good approximation for when we will know enough to have this discussion.*
> *British/American male non-parent, 65+, postgraduate, genetically tested, has genetic condition in family*

Concerns about deviating from what is ‘normal’ or ‘natural’ in reproduction

A number of respondents who answered this way were concerned about how far use of such a procedure would involve human beings venturing from ‘natural’ conception or procreation and from ‘normal’ ways of reproducing.

> *Again, this would represent a significant step towards the logic of making rather than begetting children. The acceptance of producing gametes from somatic cells in such cases could also lead to even more morally questionable use of such a procedure in cases where ideological concerns would encourage the*

> *circumventing of natural conception (for instance, producing genetically motherless or fatherless children for same-sex couples).*
> *British male non-parent, 35-44, postgraduate, genetically tested, has genetic condition in family*

> *This procedure is too far removed from the natural process of procreation and is even more drastic than genetically editing gametes / embryos. It seems excessive and unnecessary (more in the realm of scientific experimentation).*
> *Singaporean female non-parent, 18-24, graduateelors, genetically tested, has genetic condition in family*

> *I feel it would be messing with the 'normal' circle of life too much.*
> *British female parent, 45-54, secondary school educated, genetically tested, has genetic condition in family*

Some respondents were candid about their views that use of such a technique would be ‘weird’ or ‘odd’

> *This is really weird*
> *Canadian female parent, 65+, graduateelors, genetically tested, has genetic condition in family*

> *Not possible and would have exact genetics of father and not offspring - very odd thought though!*
> *British female non-parent, 25-34, graduateelors, genetically tested, has genetic condition in family*

Opposition to germline intervention in principle

Some respondents said that they objected to use of the procedure because they were opposed to any kind of germline intervention.

> *Once again, this should not be permitted when future generations would also be affected as a result of this action.*
> *British male parent, 65+, postgraduate, genetically tested, has genetic condition in family*

> *Stems cells aren't the problem. The problem is heritable alterations like this for unnecessary procedures (even if highly desired by the prospective parents).*
> *Canadian male non-parent, 25-34, graduateelors, genetically tested, has genetic condition in family*

Concerns about cloning

A number of respondents raised concerns about cloning

> *It is cloning, which is still controversial.*
> *Pakistani female parent, 35-44, postgraduate, genetically tested, has genetic condition in family*

> *This in my view amounts to reproductive cloning which should never be permissible*
> *Demographic data not provided*

> *cloning. hazards unknown and for what benefit?*
> *British female parent, 55-64, postgraduate, genetically tested, has genetic condition in family*

Appeal to intuition

One respondent admitted that their reasons for opposing use of the procedure were hard to articulate but simultaneously expressed the view that such intuitive responses were informative.

There is an element of my being that is cringing at this concept of altering the fabric of earth biology in this way. I don't think science has the tools to measure this part of me, and might suggest it is irrational and unfounded. However, my sense is that all humans have this knowing, and if they listened to it, we wouldn't even be having this conversation.
Australian female non-parent, 45-54, postgraduate, genetically tested, has genetic condition in family

Scenario 2

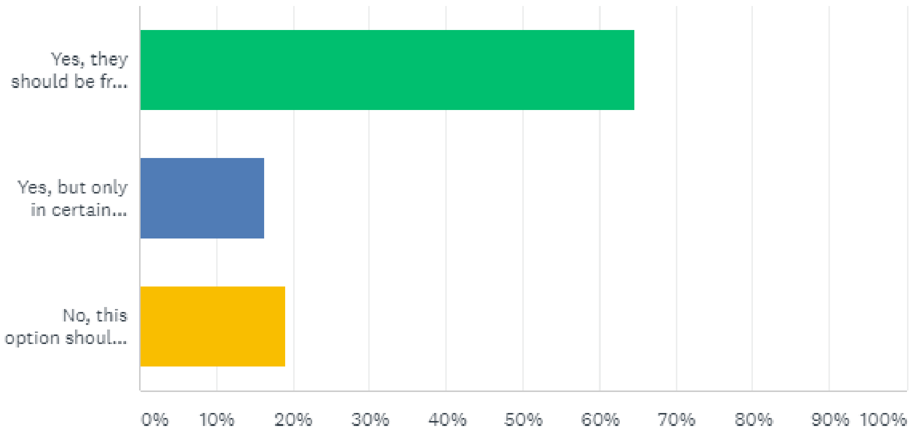
Another couple, Chris and Dara, also wants to have a family. They are not affected by infertility but a member of Chris's close family has a serious condition caused by a simple genetic mutation. As a result, that family member receives frequent intrusive, medical treatment, has reduced mobility, and 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 mutation that causes the disease to a common, non-disease variant. 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.

Question 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
187 of 289 respondents (65%)

Yes, but only in certain circumstances (please tell us what these should be)
47 of 289 respondents (16%)

No, this option should not be available
55 of 289 respondents (19%)

Respondents who answered ‘Yes, they should be free to choose this option if it is safe to use’

Benefits to the future child

One observation amongst those who responded this way was that use of the procedure would benefit a future child by ensuring they avoid the suffering caused by the genetic condition they would otherwise have had.

> *Surely this is better than bringing a child into the world knowing it will have a serious medical condition!?*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *The alternative is taking a gamble and possibly imposing a life of suffering on an unborn child.*
> *British French female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

Some respondents said that Chris and Dara have a responsibility to use the procedure or that it would be cruel not to use it.

> *I believe Chris and Dara have a moral responsibility to choose this option. They should not subject their future child to this severe medical condition, and if the only way to treat it is genetically and this option is reasonably accessible to Chris and Dara then they should do it.*
> *Australian male non-parent, 25-34, postgraduate, no genetic condition in family, has had genetic test*

> *No one should be forced to suffer from a genetic disease if it can be avoided. It is cruel to knowingly let a foetus develop given the knowledge of such a risk of disease, without allowing any form of preventative measure*
> *British male non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

One person suggested that Chris and Dara should be encouraged to use it.

> *Yes, eradicating suffering is an important goal. In fact they should perhaps nudged into using the technique.*
> *Italian male parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Public resource considerations and fairness

Another theme to arise within responses was that use of the procedure would yield financial savings in terms of treatment and care that would not be needed. This would have implications for the NHS and state resources more widely, potentially.

> *Financial costs to public health and care sector are high; emotional costs to family likely also.*
> *Welsh female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *Costs of medical treatment for a child born with this condition…*
> *British female parent, 55-64, graduate, genetic condition in family, has had genetic test*

One respondent referred to the approach that the National Institute for Health and Care Excellence (NICE) take when developing clinical guidance.

> *Subject to NICE Guidelines view of cost:benefit, and how the DNA amendment will affect in terms of social healthcare costs. If the cost of pre-treating a potential embryo to prevent the disability is greater than the cost to society of treating the*

> *disease, as it sounds from the description, then likely NICE would advise treatment…..*
> Demographic data not provided

Reproductive choice and basic freedom

Some respondents mentioned individual freedom Chris and Dara should have to make their own decision about whether to use the procedure or not.

> *Same as before: basic freedom, consenting and informed adults, no third parties harmed.*
> *American male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

> *Ultimately it's their decision to have children .If the opportunity to have children free from the defective gene and have a normal healthy baby then surely they should be given this opportunity.*
> *British male non-parent, 65+, O level educated, no genetic condition in family, not genetically tested*

One person also suggested that the decision to make of the procedure was a private matter for Chris and Dara.

> *Their medical choices are their own business.*
> *American female non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

Interest in having a genetically related child

A number of respondents alluded to the importance to people of having the opportunity to have genetically related children

> *It's important to give them the chance to have a child*
> *UK female parent, 35-44, graduate, no genetic condition in family, not genetically tested*

Some expressed this idea by appeal to the idea that people have a *right* to have genetically related children.

> *If the alternative is a debilitating and horrible condition, then yes - and everyone has the right to have children if possible.*
> *UK male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *The desire to have a healthy child is a right for a couple.*
> *Pakistani female parent, 35-44, postgraduate, no genetic condition in family, has had genetic test*

The procedure would be on a par with medical treatment

One line of response was that to use the procedure would be similar to administering a medical treatment to a person (though added that the availability of pre-implantation genetic diagnosis (PGD) might be relevant to whether Chris and Dara should use it).

> *We have some of the same general issues we had with Ali and Brian (reproductive liberty as a negative right; justice and how that affects whether all persons have access to this tech; pronatalism and the strenot genetically testedh of cultural imperatives to have genetically related children even at great cost). That said, this strikes me as being a clear treatment imperative. If we could alter a grown person with genetic therapy so that, for instance, their copies of genes that cause cystic fibrosis were replaced with genes that did not, this would be acceptable to me.*

> *Altering an embryo in this way is similar. I do wonder if it would simply be possible to do pre-implantation genetic screening on these embryos, and choose to implant only those embryos which are free of the genetic condition.*
> *American female parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

Another respondent thought that the procedure was morally on a par with other kinds of unspecified medical treatment, citing safety as the only salient consideration.

> *There's no difference between selecting a potential child's genes and giving them a medical treatment after birth. The only relevant question is what the most effective remedy is.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Respondents who answered 'Yes, but only in certain circumstances (please tell us what these should be)'

Only for conditions that significantly affect quality of life

Many respondents said the procedure should only be used to prevent conditions that had significant implications for quality of life.

> *Yes but only for medical conditions which cause significant harm or pain.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *I think it would all depend on the quality of life the child would have with this condition. If the person was going to be severely disabled and live basically as a vegetable, it may be more considered versus a child that will have to undergo some procedures and regularly visit a doctor but live a relatively 'normal' life (even if reduced).*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

One respondent making this point suggested that Down's syndrome and other disabilities would not count as targets for the procedure.

> *It would depend on the specific disabilities. Many people with Down's syndrome and other disabilities can live normal lives despite their disabilities. Many people see disabilities as part of who they are. As this is an undefined disability, it is hard to judge, but I would think from the information available that it could be considered as an option.*
> *British female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

If the procedure is safe

A number of respondents said that the acceptability of the procedure would depend on whether or not it was safe and the implications of its use fully understood.

> *The consequences of removing this genetic variant have been fully considered- e.g. carrier state of some genetic disorders is beneficial in some circumstances (CF, sickle).*
> *British male parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

> *As before - depends on the safety assessment, the specific gene etc*
> *British female parent, 45-54, postgraduate, genetic condition in family, has had genetic test*

One respondent said that use of the procedure would only be acceptable under these circumstances and added that the level of knowledge required for the appropriate level certainty about safety would never be achieved

> *My concerns are identical to the previous scenario. How do we know this is "safe"? How can we ensure that it is safe before testing in humans? I do not believe this is possible. Animal models will not be sufficient. Our understanding of multi-gene interaction is insufficient to ensure that the benefits (avoiding the debilitating disease) outweigh the consequences not only to the resulting child, but to future generations beyond that child.*
> *American male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

If the procedure is monitored and there are legal protections

A number of respondents said that it would be acceptable to use the procedure as long as the appropriate legal frameworks were in place.

> *Again, as with the previous example, the procedure is 'good' as it reduces harm or potential harm caused by what seems to be quite a debilitating condition. I am saying yes in certain circumstances as I would insist on the same legal and regulatory framework as mentioned in the previous example, with each application to use gene editing considered on a case-by-case basis by the HFEA.*
> *UK male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*
>
> *If decision also governed by parliamentary and specialist bodies depends on the level of risk depends on cost-effectiveness and safety of alternative options not involving a genetically related child depends if Chris and Dara have been able to come to a fully-informed consensual and mutual decision.*
> *UK female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Again, it was said that though the procedure might be acceptable if legally mandated, use of PGD might be a better option.

> *The circumstances should be prescribed by legislation. In my view preimplantation genetic diagnosis to find embryos that do not carry the disease variant is far more preferable to genome editing*
> *Demographic data not provided*

If Chris and Dara have first considered or tried alternatives to the procedure

Some respondents said that it would only be acceptable for Chris and Dara to use the procedure if they had considered, or tried out, other means of becoming parents first.

> *Yes, if embryos selection is not a practical alternative*
> *UK male non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*
>
> *They should have tried PGD first*
> *UK female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

One respondent specified that these alternative routes should include adoption, and questioned whether the NHS should pay for prospective parents to undergo this procedure, given the availability of other options.

> *All other options of being a parent without being biologically connected should be explored first as preferable. Also should a public health system pay for this when they could become a parent through other routes?*
> *Scottish female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

One respondent said that it Chris and Dara should be encouraged to use these alternative means of becoming parents.

> *If possible, they should be persuaded to adopt a child or use donor gametes and only in exceptional circumstances where they are unwilling to do that and would rather go for having a sick child rather than an adopted one they should be offered the procedure just so that their offspring doesn't suffer their decision.*
> *Bulgarian female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

If Chris and Dara have been offered genetic counselling

Some respondents said that the procedure should only be used after they have been given access to genetic counselling.

> *We tend to go straight for an ethical debate in these issues instead of ensuring that families have excellent genetic information and counselling. Chris and Dara should be able to meet people and parents of those with the condition, they should be deemed to have a good understanding of what it would mean to them, the statistical risk, the support on offer etc etc. There should also be a frank and open discussion about this technique. This consultation should be detailed and last several weeks before the family decide, rather than being given as routine to avoid 'less than perfect' babies. The regulation really needs to be around these issues rather than the technique itself.*
> *UK female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*
>
> *After counselling, and embryo must be checked for viability.*
> *UK female parent, 65+, graduate, no genetic condition in family, not genetically tested*

Concerns about societal impacts

One respondent warned about the possible societal implications

> *What is better; to not exist as you know yourself to be, or to exist as a different person or to allow a person without disease to exist? On balance it is probably best to exist as a potentially different person but the perception of disease and disability is a spectrum which is perceived differently by all and the spectre of a Gattica-like society must be considered.*
> *UK female parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

Respondents who answered ‘No, this option should not be available’

Availability of alternative options

The availability of alternative means of becoming parents, including PGD, prenatal screening and adoption, was a theme in comments of those who responded negatively to this question.

> *Why is human genome editing being preferred over other methods, eg such as screening embryos. Although PGS and PGD are ethically contentious also, surely they are preferable to altering the human genome when so many unknowns exist.*
> *Australian female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *This is not a neutral question -- if the reader responds no, they are essentially denying this couple a healthy child. This couple would have the option of PGD, sperm donation or adoption -- there is absolutely no reason to edit their future child's genes. See #1.*
> *American female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *Adoption is a better option*
> *Demographic data not provided*

> *Chris and Dara could use PDG to select an embryo that does not carry the condition.*
> *American female parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

Concerns about societal impacts

Some respondents expressed worry that the procedure would ultimately be used to alter non-medical traits, with some mentioning eugenics specifically.

> *I'm concerned that other non-medical, or less serious medical, conditions would then be considered under the same rules. The thin end of the wedge argument I know, but societal differences count different conditions as more dire and dangerous & if there turns out to be a genetic component to a condition, the opportunity to use this technology would be attractive.*
> *Australian/British male non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

> *Concern round what this means for disabled people to begin treating them as editable out of the population - eugenics*
> *American/British male parent, 35-44, graduate, genetic condition in family, not genetically tested*

> *It's eugenics.*
> *Italian male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Safety and uncertainty of long-term consequences

Issues relating to our understanding of the long term effetcs of use of such procedures were raised by some respondents.

> *Unpredictable outcomes of altering genome.*
> *UK female parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *Permanent modifications to the embryos must not be allowed. Some risks to the procedures might not be known yet... think about the use of Thalidomide in North America...*
> *Canadian male parent, 55-64, postgraduate, genetic condition in family, has had genetic test*

Special status of embryos

Some respondents raised concerns about the treatment of embryos that would be involved in the procedure.

> *Reproductive technology which creates and rejects surplus embryos does not treat embryos with the respect they warrant*
> *UK female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *The apparent treatment of embryos required by such a procedure represents a unhealthy shift in posture towards human nature.*
> *UK male parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

One respondent expressed this as a concern that the procedure would enable Chris and Dara to design their children

> *….Allowing this procedure would give Chris and Dara too much power to design an embryo according to their wants, which should not be permitted.*
> *Singaporean female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

One respondent also alluded to issues relating to fair access.

> *I may end up responding in the same way to all of these scenarios. I don't have any concerns about the technology in itself. I am more concerned about the public and social implications of investing large amounts of money in ensuring wealthy people can have genetically related offspring, when the world is full of existing children who need parents*
> *Australian female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

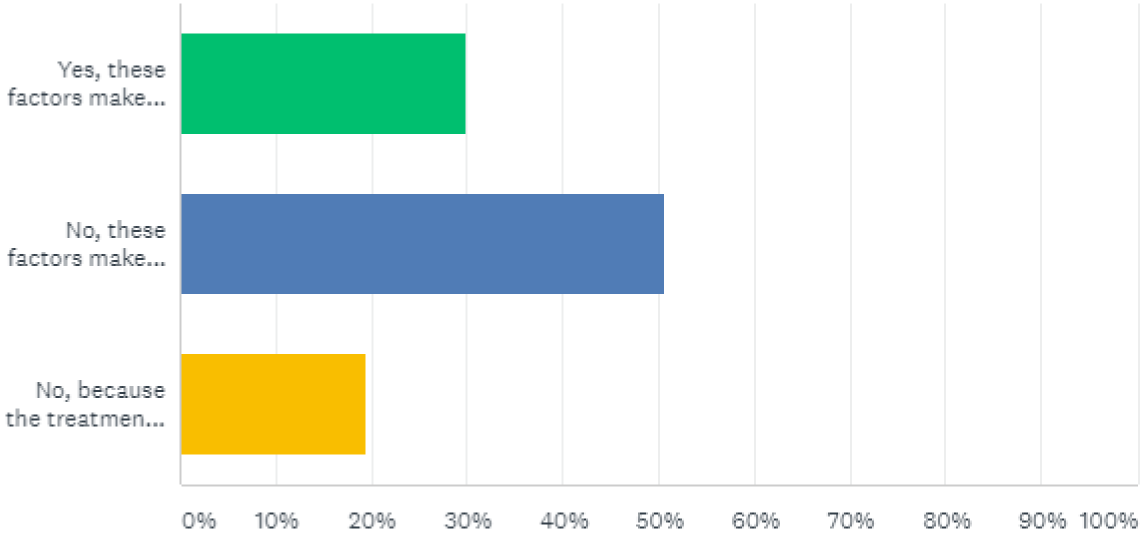
There is no right to genetic parenthood

One respondent said that there are no absolute rights to have genetically related children and suggested that alternative options are pursued by people who want to become parents.

> *No-one has an absolute right to their own biologically related child. They should be counselled to use one of the many other options to acquire a child if they want to.*
> *Australian male non-parent, 65+, postgraduate, genetic condition in family, not genetically tested*

Question 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
86 of 288 respondents (30%)

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
146 of 288 respondents (51%)

No, because the treatment should not be available
56 of 288 respondents (19%)

Respondents who answered ‘Yes, these factors make a difference; there should be restrictions on when the procedure may be used

The probability of the child developing the condition is quite high

Some thought that the probability of the future child having the condition was important. One respondent said that if the likelihood that the condition would be present was low then screening might be a preferable option

> *If it is a very low probability, why not screening the embryos? It wouldn't make a difference if the consequences were anything that will impact on daily life of the individual.*
> *French female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

Respondents individually cited different probabilities as those that marked the threshold of acceptability for use of the procedure

> *There are low risks of a child being born with a variety of problems. I don't think it is acceptable to use procedures like this, unless the risk is substantial (at least 20%).*
> *French female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *For me only the following factor would make a difference: … if there were a much lower chance of the child developing it (say, 3-5%)*
> *British male non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

The condition causes cognitive rather than serious physical disability

Some respondents said that it would not be acceptable to use the procedure if the condition targeted caused a learning or cognitive disability which seemed different to a serious physical disability.

> *A mild cognitive impairment seems like quite a different thing. Editing out autism would definitely be too far and this seems like something on that scale. The important thing is that someone with a mild cognitive impairment might be quite happy and able to contribute to society - perhaps happier than they would be without it. Drawing the line would be difficult, but that's not to say it's not worth drawing.*
> *British female non-parent, 35-44, postgraduate, no genetic condition in family, genetically tested*

Some added that to use the procedure to target such conditions would devalue people living with those conditions or undermine diversity.

> *By editing "less serious" conditions - or any condition for that matter - it somehow devalues people who have these conditions and are happy with their life. For example, many people with Down's syndrome lead happy fulfilling lives and wouldn't be any other way!*
> *British female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *It is dangerous to say that a mild cognitive impairment is not desirable. These people are also a part of the beautiful diversity you see in the human race. So we should not aspire to prevent these people from existing…*
> *Dutch female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

A combination of the factors described are relevant

A number of those that responded this way said that different combinations of the factors cited were important

> *I think that this procedure should only be used when there is a high likelihood of inheritance and the condition is serious or life threatening*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *I would probably only consider such an approach appropriate if the condition was severely life limiting, chronic and that inadequate treatment was available; however I am also sure there are exceptions to this rule.*
> *British female non-parent, 18-24, college educated, no genetic condition in family, not genetically tested*

> *If the chance of the child developing the disease was low then genetic treatment should not be used. It should also only be used if it leads to a serious disability rather than a mild disability, as we still don't know enough about the disadvantages and advantages of certain mild "disabilities". For example, some people with Asperger's, which is considered a disability, may have impairments in certain areas but have benefits in other areas. This heterogeneity in the population may be advantageous to us as a whole.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

And some said that all the factors described are relevant

> *These factors all make a significant difference on whether the technique should be used. The Mitochondrial Donation Regulations make numerous references to a "significant risk" of "serious mitochondrial disease" as grounds for issuing a licence. While the terms "serious risk" and "significant... disease" are not exactly specific, it could be argued that a 3-5% risk is not 'significant', nor mild cognitive impairment 'serious'.*
> *British male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *All factors should be taken into consideration and whether or not it is possible to determine the child's quality of life. And also whether it would be possible for them to conceive a healthy child naturally (as in no genetic interference but with usual IVF screening)*
> *British female non-parent, 18-24, college educated, no genetic condition in family, not genetically tested*

Slippery slopes

Another concern raised by respondents was that use of the procedure would initiate a 'slippery slope' towards uses of the procedure that are unacceptable, such as for the alteration of traits associated with minor conditions.

> *There is a slippery slope when we talk about desirable genetic traits. Particularly when it comes to disability rights, we need to tread very carefully when it comes to these type of issues.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *There needs to be a line drawn at some point so that embryos are not altered for only minor conditions*
> *British female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

Equality and diversity

Points about the implications for issues such as equality and diversity were made. Concerns that inequalities might emerge or be exacerbated, or that societal diversity might be reduced, if the procedure were to be used in certain circumstances were expressed.

> *I think the overall effect of allowing a particular gene therapy should be an increase in equality and the overall well-being of a community. I become more apprehensive about gene therapies as the traits they are 'fixing' become less severe. I do not like the idea of children who received gene therapies having a bigger societal advantage than the mean.*
> *Australian male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

> *…Factors that reduce the severity of the disease should affect our readiness to use genome editing to 'wish it away', else we risk erasing diversity of thought and people in the quest of 'perfection'.*
> *British female non-parent, 18-24, genetic condition in family, not genetically tested*

Respondents who answered ‘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’

Reproductive and personal freedoms

One view expressed within the comments of Respondents who answered this way was that Chris and Dara should be free to make their own decision about whether to use the procedure.

> *Parents should be able to decide on the layout of their family, including any procreative decisions, in PRIVATE and without interference of anyone else (except for when they solicit medical/scientific counsel)*
> *Demographic data not provided*

> *I was inclined to yes at first but then thinking about it, I think it's in the parents' hands anyway and some other factors, not mentioned here, may affect their decision. To me they make no difference. I would decide as a parent if I want this risk to be taken, just how I would decide to keep a child with problematic karyotype.*
> *Greek female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

It was suggested by one respondent that Chris and Dara would be likely to have insights into the implications of having the condition, which counted in favour of allowing them to make the decision about whether to use the procedure.

> *Based on the scenario, Chris will know about the effect of the illness, and have made opinions based on that. Dara may well also have a great deal of information and experience through knowing Chris. They are the people bringing a child/children into the world, and it is up to them to decide what risks are acceptable.*
> *British male parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

One respondent observed that though these factors should not determine whether or not Chris and Dara were able to use the procedure they might feature in the individual decision taken by the couple.

> *These factors may influence the couples' decision, but I don't believe they should be a part of the regulations on when the technology is allowed. 'Seriousness' of a condition is a subjective judgement*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Minimisation harm to the future child

Some respondents said that the listed factors were not relevant because the most important consideration was fact that the procedure would prevent or minimise harms to the future child.

> *You kind of forced my choice here... These factors shouldn't make a difference, but not because Chris and Dara should have the choice, but because it would be better to eliminate this issue than to put the child through cognitive impairment, later onset or invasive treatment.*
> *Australian male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *It's always better to create a child with a better expected life than one with a worse expected life.*
> *American female non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

> *A caveat: the reason given, that Chris and Dara *as the future parents* should be able to decide is not a good reason. The reduction of possible harm is more important in my opinion.*
> *German male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *This is a procedure that will prevent a negative human condition. Do not care. There is no downside. I am not a vitalist.*
> *American male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

The described factors are relevant but should not ground restrictions on access to the procedure

It was said by some respondents that the factors described in the question should be relevant to individuals' and couples' consideration of whether to make use of the procedure, but should not constrain their access to it

> *No, though I would hope it would affect Chris and Dara's thinking about the situation.*
> *British male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *These factors make some difference, but not enough to justify denying the procedure, given the amount of suffering involved….*
> *Demographic data not provided*

Public resource considerations

Some respondents observed that the cost of the treatment would be less than treatment for a child with the condition

> *No difference except obvious differences in cost-effectiveness, that would be then dependent on this being paid in a private clinic or part of universal healthcare(my preference) (I'm not implying universal healthcare is 'free' or has infinite money) See*

> *previous answer, would it make a difference for cures that are a pill or somatic gene therapy?*
> *Spanish male non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

One respondent went further and stated that the financial implications for the NHS of having a child with the condition meant that Chris and Dara had a responsibility to use the procedure.

> *The cost of ongoing medical care for a condition (no matter how likely or what type/when it will affect the health of the individual) that was avoidable is not justified (unless the family pay for it themselves). Therefore to save the NHS money, they should have the procedure.*
> *British female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Respondents who answered 'No, because the treatment should not be available'

Uncertainty about long term consequences

Concerns about the safety, risk and uncertainty about the long term effects of use of such procedures were raised by some respondents.

> *Don't change human germ plasm because of unknown long-term risks.*
> *Canadian male parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

> *If, as suggested above, no 'excess' embryos are created, then the question becomes a simple matter of the balance of risk. As in all medical matters of judgment, potential benefit must outweigh potential risk for the action to be ethically justifiable*
> *British male parent, 65+, postgraduate, genetic condition in family, not genetically tested*

> *As previously stated, the future of the human community as a whole takes precedence over the desires of any particular couple.*
> *American male parent, 65+, postgraduate, genetic condition in family, not genetically tested*

Availability of alternative options

Some respondents raised again the availability of alternative options of becoming a parent, suggesting that PGD or adoption were preferable to the use of procedures based on genome editing.

> *No because they have the option of PGD so embryo editing is not needed in this situation.*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

> *Adoption is a great option if they didn't want to risk having a child naturally*
> *Australian male non-parent, 45-54, postgraduate, genetic condition in family, genetically tested*

One respondent suggested that there were independent, positive reasons to adopt in view of the fact that some children are 'abandoned' and in need of parents.

> *And knowing that they are likely to have a child with impairment should be enough to encourage them to adopt. Until we have fixed societies' abandonment of children (especially that which is driven by economic reasons) adoption must be favoured over fertility treatment and gene therapy.*

> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Concerns about societal impacts

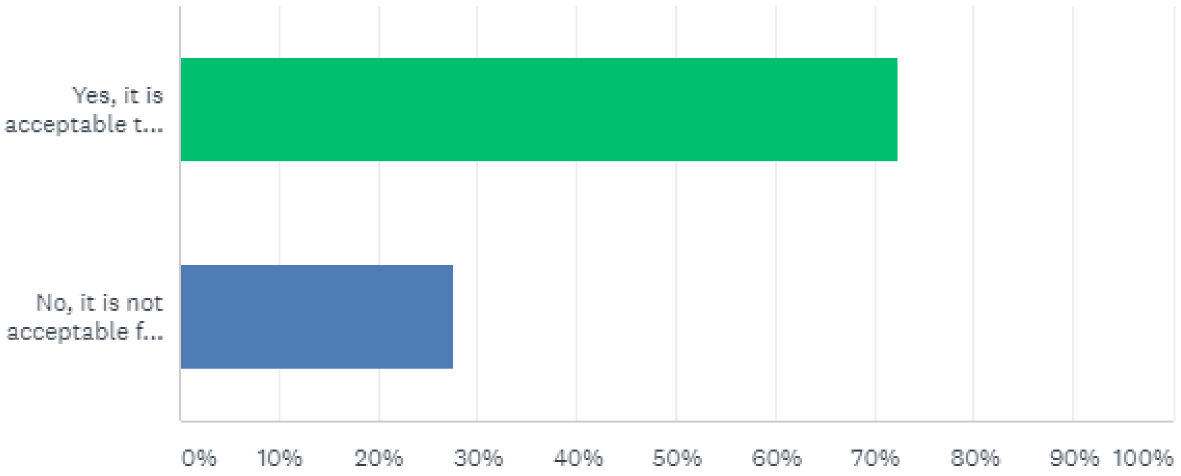
Concerns about prejudice, eradication of disability and eugenics were also raised by one respondent.

> *One also needs to be very careful not to be prejudiced against people who live with disability. I find the underlying eugenic goal of wanting to eradicate all difference (aka disability) very concerning.*
> *Australian female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *Altering the human germline is NOT an individual decision but one that affects wider society*…
> *America female non-parent, 35-44, doctorate,genetic condition in family, not genetically tested*

Question 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
208 of 287 respondents (72%)

No, it is not acceptable for them to travel abroad for a treatment that is illegal in the UK
79 of 287 respondents (28%)

Respondents who answered ‘Yes, it is acceptable to seek treatment abroad’

Personal freedom and choice

A number of respondents cited personal choice and the rights of Chris and Dara to make their own decision about travelling to access the procedure

> *This is their right if they decide to do so. I hope their UK doctors would support them with questions and information they need before they go for the treatment.*
> *British female non-parent, 55-64, graduate, genetic condition in family, genetically tested*

> *It is their decision*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *This is down to personal choice and if the couple feel that this is their only option then it should be down to them to make it, having taken advice from the relevant medical professionals and done proper research into why it is illegal in the UK but not in the other country.*
> *British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

The procedure should be legal in the UK

Some respondents said that the reason it would be acceptable for Chris and Dara to seek the treatment abroad was that they should be able to access it in the UK.

> *I think in this particular scenario this treatment should available in the UK and so in turn, it is acceptable for Chris and Dara to do what is necessary to make it available to them. If however, the prohibition of this treatment came about as a result of careful considerations made by ethicists, scientists and policy makers, then I would deem this act as being less than ethically ideal, but understandable.*
> *Australian male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

> *Escaping repression in one's own country is of course always ethical.*
> *American male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

One respondent said that they thought Chris and Dara had the right to travel to other countries to access procedures such as the one described in the example, but added that they thought that the acceptability of the particular decision might depend on the specific treatment.

> *I personally believe this treatment should be acceptable in the UK, however in the case of some other treatments that are perhaps less ethical (though none come to mind), I may not find it acceptable to circumvent UK law, though objectively I believe they should have the right to do it.*
> *British male non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested*

Prohibition would be impractical

A number of respondents said that attempting to restrict people from leaving the UK in order to access the procedure would not be practical.

> *Making this illegal to receive this treatment seems difficult and costly to enforce.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *How would you ban it? Seal the borders? Ban planes? Cut off the Internet?*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

One respondent who said that it would be impossible to enforce a policy preventing people from travelling to seek the treatment added that this raised concerns about the availability of counselling and support in countries outside the UK.

> *I would be extremely concerned about couples travelling abroad where they may not get the counselling and support they need etc, however it is basically un-policeable. That is why we should allow it in the UK, but with certain provisos about supportive care etc.*
> *British female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Principles relating to free movement

Some respondents said that it would be wrong on principle to stop Chris and Dara travelling to access the procedure since this would breach the couple's rights to leave the UK.

> *As citizens of the UK they are obligated to abide by the extant law. However, all citizens have right to travel as permitted by international passport control and granted visas, in which case if they travel for the purpose of an elective medical procedure, then this is within their rights.*
> *American male parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

> *Is the UK now a prison?*
> *American male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

One respondent clarified that their view was that this right should not be impinged upon, irrespective of the acceptability of the procedure itself.

> *This is an issue of their freedom of movement. But the ethical issues around the procedure itself remain. In my opinion, the procedure should not be available for the reasons stated above.*
> *American male parent, 65+, postgraduate, genetic condition in family, not genetically tested*

Ethical considerations are not identical to legal considerations

Some respondents made the observation that legal and ethical considerations were not the same and that the fact that the procedure might be illegal in the UK did not demonstrate that it would be wrong to leave the UK to access it.

> *This question is pointless and I'd rather would not answer it at all. The legality of the situation can't be considered an ethical question. - Homosexuality was once illegal in my home country. That was retarded. Legality renders nothing in the right or wrong in itself.*
> *German male non-parent, 35-44, graduate, no genetic condition in family, not genetically tested*

> *Laws have no bearing in morality. The legality or illegality of an action is not a morally significant consideration.*
> *American male non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

On the condition that there are no costs to the NHS

Some added a caveat to their response that if a couple chose to use their freedom to access a procedure illegal in the UK abroad, then they should accept that any resulting healthcare problems in their future child should not be covered by NHS.

> *But there can't be any ramifications (e.g. cost of aftercare) for UK health services if they do.*
> *British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

> *That's up to them... if one is determined, one can do anything... but they must take all responsibility... should the state pay for the child's healthcare if the parents ignored ALL advice to the contrary? Perhaps they should be required to take out private medical insurance for risky medical techniques that will pay for it... from the moment they conceive.*
> *British male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

> *Yes, so as long as any associates health costs are payed by the couple and not the government.*
> *Australian female non-parent, 18-24, graduate, no genetic condition in family, not genetically tested*

Value of internationally co-ordinated regulation

Some respondents suggested that the possibility of medical tourism demonstrated that there should be international coordination on the regulation of procedures

> *Ideally, laws should be harmonised internationally*
> *Demographic data not provided*

> *That's why it's important to have good international harmonisation on these issues. One cannot deny individual decisions to take treatments abroad. But a concern is of course whether the treatment abroad is provided on correct ethical considerations*
> *Dutch male parent, 45-54, postgraduate, no genetic condition in family, genetically tested*

A related point made was made by one respondent who predicted that this kind of scenario would ultimately encourage all countries to legalise use of the procedure.

> *Will eventually be permitted everywhere for this reason..*
> *Czech male non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

Concerns about lower clinical standards outside of the UK

Concerns about the quality of the treatment that Chris and Dara would receive in some parts of the world were raised.

> *Once such treatments were made available many parents would be highly likely to seek treatment - wherever it is available - possibly even places with worse clinical standards than those in the UK. The results of this would likely be far worse than attempting to prevent them from seeking the treatment at all.*
> *British non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *The difficulty with such medical tourism comes from concerns that the overseas clinic is NOT held to the same clinical standards as the UK. If they are however, there is no reason to prevent travel for its use.*
> *British male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Concerns about societal impacts

It was pointed out that only those with means would be able to access the procedure this way, which raised issues of social justice.

> *I get that medical tourism in this topic is a valid concern, best avoided due to inequality etc. but I can't say 'unacceptable' and be honest/consistent/not a hypocrite: if it was my child I would do the travel option.*
> *Spanish male non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *It's acceptable for Chris and Dara, but I feel like this is a slimy way for the UK government to avoid making something legal that they should (similar to euthanasia). It makes it so that the procedure is only available for the rich, which to me isn't acceptable. We're supposed to have a national health service.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Respondents who answered ‘No, it is not acceptable for them to travel abroad for a treatment that is illegal in the UK’

It would be wrong to use the treatment

Some respondents expressed the view that use of the treatment would be wrong in itself and argued that this meant that it would be unacceptable to access the treatment, even in countries in which it was legal.

> *It is never acceptable to undergo this treatment.*
> *British female non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

> *If it's unethical here, it's unethical anywhere*
> *British female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *If ethics means anything, it means that people should not be able to evade their ethical obligations by going to another country which happens to have different laws.*
> *British male parent, 55-64, postgraduate, genetic condition in family, genetically tested*

It would be wrong to evade UK Law

Some respondents felt that it would be wrong for Chris and Dara to travel to access the treatment since this would involve circumventing the laws of the land in which they live.

> *They should abide by the laws of this country, informed by majority ethical consensus in this country.*
> *British male non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

Some respondents compared such activity to tax avoidance.

> *In the same way, as it is ethically unacceptable to bypass UK law with respect to tax havens, this is also unacceptable.*
> *British male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

> *Evading the law, for instance to avoid taxes, has never been acceptable, even if loopholes exist.*
> *British/American male non-parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

Concerns about societal impacts

Issues relating to fair access were also raised as ones associated with medical tourism.

> *Not enthusiastic about medical tourism as it has a tendency to trickle down to developing countries and affecting a vulnerable population. An example is organ tourism.*
> *Pakistani female parent, 65+, postgraduate, genetic condition in family, genetically tested*

> *Medical tourism causes problems concerning safety regulations, as well as fairness of access to procedures.*
> *American female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

Illegality in the UK would indicate ethical or safety issues with the procedure

Some respondents said that given the UK's more liberal stance on reproductive technologies, if it was illegal in the UK this would be likely to indicate that there was a good reason, relating to ethics or safety, for it being restricted

> *The UK is very advanced in comparison with other countries (see mitochondrial donation for ex), if something is not allowed in the UK, I would think there is a very good reason why (safety and/or ethical concerns not present in other country?).*
> *French female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *It might not be safe to them/ child. Also there's usually a reason why the procedure is not available in the UK.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Consequences for the NHS

Some respondents were concerned that if Chris and Dara travelled to access treatment there would be consequent costs for the NHS.

> *If there were any complications later then why should the NHS treat a procedure that is illegal in the UK.*
> *British female parent, 45-54, secondary school educated, genetic condition in family, genetically tested*

> *Because the UK will end up paying for the results forever.*
> *Canadian female parent, 65+, graduateelors, no genetic condition in family, not genetically tested*

One respondent expanded on this point by claiming that couples do not have rights to have perfect children.

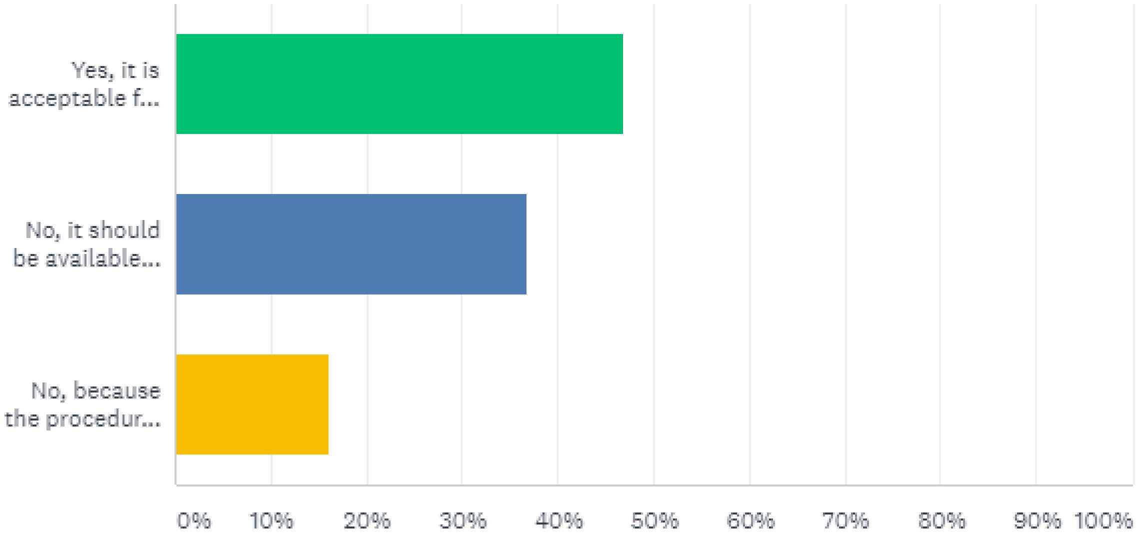
> *Because if anything goes wrong the NHS will pick up the tab. Not being able to have children, or to produce perfect children is not a right or an illness to be treated as one.*
> *British female parent, 65+, graduateelors, no genetic condition in family, not genetically tested*

Another respondent suggested that there might be practical issues for the NHS in treating a child that had been born as a result of a procedure that was not legal in the UK

> *I would find it concerning if prospective parents avoided the law in this way, depending on why the law had been made. For example, if the procedure turned out to be unsafe and the child was negatively affected, it might be difficult to deal with this within a country that had not sanctioned the procedure in the first place.*
> *British female parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

Question 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
136 of 290 respondents (47%)

No, it should be available to everyone in a similar position if it is available at all, and public authorities should ensure this
107 of 290 respondents (37%)

No, because the procedure should not be available to anyone
27 of 290 respondents (9%)

Respondents who answered ‘Yes, it is acceptable for the procedure to be available without there having to be equality of access for all’

On a par with other privately available treatments

Some respondents observed that there already exist a number of privately available treatments that are available only to those with the means to access them.

> *Private medicine already offers an unbalanced advantage to those able to afford it. If private provision were subject to the same extremely restrictive approval procedures suggested above it might have an advantage of allowing a limited exploration of the failures and successes prior to the likely reduction in cost and more widespread availability in the future.*
> *British female parent, 45-54, postgraduate, genetic condition in family, genetically tested*

> *Not too dissimilar to current infertility treatments, I believe? Many couples can only afford a set number of rounds of IVF, for example.*
> *Welsh female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

Equal access would be better but not necessary to justify any use of the procedure

A number of respondents expressed the view that though it would be preferable for everyone to be able to access the procedure, this did not mean that it would be acceptable to prevent private access for those with means in the event that the NHS did not offer it to patients.

> *Whilst it would be ideal for this procedure to be available for all I wouldn't have objections to it being offered privately. But there are other option for other couples such as adoption etc.*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *It should be available to all, but if Chris and Dara can afford the treatment it is their decision to pay.*
> *British female non-parent, 18-24, college educated, no genetic condition in family, not genetically tested*

Some respondents contextualised this point, making the aforementioned observation raised by other respondents that there are other kinds of healthcare treatments that only those with means can access.

> *It is a fact of life in the UK that rich people get things that poor people don’t – schooling, housing, healthcare. I’d much rather it was free to everyone, but that shouldn’t meant banning it for those who can afford it. Some people may make huge sacrifices to find the money – doesn’t mean they are well off*
> *British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

> *There are overwhelming ethical concerns for making such a treatment available to limited groups of people only. But the same is already true for existing medical treatments! Changing this is desirable but beyond the question of the ethicality of genetic treatment.*
> *German male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Private use would bring the cost of the procedure down

An observation made by some respondents was that use in the private sector might have the effect of driving further developments that would result in the cost of the procedure coming down. This might ultimately mean that those without means to access the procedure privately in the short term might be able to do so in the future when it was less expensive and/or inexpensive enough to be made available on the NHS.

> *That treatment is accessible to all is the most preferred situation. However, as history shows, first medical innovation tends to become available privately, with time moving into publicly affordable scale. Private availability acts like the first-tier "experiment" before it is expanded en mass*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *Really difficult, but if by using the treatment it meant that more data on it could be established perhaps cheaper or more cost-effective ways could be found. I think sadly this is the case for most things that certain people can afford it and others not, I don't think this means it shouldn't be offered but it should be offered with an aim to try to make it more broadly accessible asap.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *I find this very difficult to answer as I believe equal access to healthcare to be important. However f it means that the treatment develops and may become something that could be provided more cost effectively in the future I would find it more acceptable.*
> *British female parent, 55-64, graduate, genetic condition in family, genetically tested*

Rationing of public resources is justified

A point made by a number of respondents was that the NHS is obliged to make decisions about offering healthcare procedures to patients in a wider context of public healthcare provision and budgetary considerations which must take account of the costs of such procedures. This meant, they said, that taking account of value for money or rationing resources available was appropriate.

> *It is fair for the NHS to ration the resources available to it and to decide what they can and can't afford to offer. If they have other ways of financing it which will not burden the NHS then that is their prerogative.*
> *British female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *The NHS has the right to consider value for money in the procedures it funds. We must accept that as part of a public healthcare system. Chris and Dara's situation is unfortunate but the money spent on the procedure could be best spent elsewhere.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *I don't believe there has to be complete equality of access, because there should be limits on what the state should have to pay given the opportunity costs involved. But it is sad if the rich can get something and the poor cannot. In which case, this needs to be sorted out at a societal level.*
> *British male parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

Challenge to the idea that genetic parenthood is important

One respondent questioned the need for prospective parents to find ways of having children that are genetically related to them

> *Having your own child is not critical to life or to long term happiness. Therefore although it is inequitable there have to be such decisions in all aspects of life. The poorer person is not able to afford it and the country cannot afford it so why should it be given when adoption is also an option. Wealthy people have many advantages and even health benefits are one of them.*
> *British female parent, 55-64, postgraduate, genetic condition in family, genetically tested*

> *Whilst it would be ideal for this procedure to be available for all I wouldn't have objections to it being offered privately. But there are other option for other couples such as adoption etc.*
> *British female non- parent, 25-34, graduate, no genetic condition in family, genetically tested*

Availability on the NHS would send the wrong message

One respondent expressed concerns about the implications of making the procedure available on the NHS, arguing that this would send a message that the procedure should be used.

> *My stance is that the procedure should not be available when used to treat non-fatal genetic diseases. However, if Parliament legalises the treatment for a broader range of diseases, then market forces will unavoidably determine whom the treatment is available to. Firstly, gene editing is a drastic measure that is unlikely to be widely-sought. Secondly, it would be unwise to get the NHS to foot the bill such that the treatment is available to all for the same price: that would send the message that the treatment should be used widely as a default option. This is an undesirable message. It would overburden the (already overburdened) NHS. So, whilst it may be unfair to allow market forces to determine the price of the procedure, this is a necessary evil to effectively limit the spread / popularity of gene-editing treatment.*
> *Singaporean female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

Respondents who answered ‘No, it should be available to everyone in a similar position if it is available at all, and public authorities should ensure this’

Wealth should not determine health

Many respondents argued in their comments that it would be unfair for the procedure to be available only to wealthy people.

> *It is important that such procedures are available for all and not just the wealthy.*
> *Singaporean female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *I think it's unfair for people to get special treatment just because they happen to have more money*
> *Demographic data not provided*

> *I strongly disagree with people’s wealth, class, status etc determining their genetic advantages.*
> *British male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

Concerns about societal impacts

Some of the concerns raised about equal access and unfairness were linked to deeper concerns about the wider consequences for society of allowing better-off individuals and couples to access the procedure while those with less means were unable to access it.

> *It won't take many generations for a two tier (or more) society to develop where 'bad genes' are locked into those who cannot afford to get rid of them. A Brave New World etc.*
> *UK male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *Direct modification of human germ plasm should be equally available to all; otherwise we have a potential for the well off to design their offspring. This is the definition of plutocracy.*
> *Canadian male parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

One respondent highlighted the tension between the allowing people the freedom to use their wealth as they chose, including for healthcare treatments, and the realising a fair and just society.

> *At the end of the day I think promoting overall well-being of a society should be centre of mind. It may be that while these therapies are the best thing for the individual, they may reinforce class-systems and be worse for a community as a whole. I DO think it's acceptable for Chris and Dara to pay for the treatment if it was expensive, just as I think it's acceptable for the wealthy to pay for expensive surgeries not covered by the NHS that increase their lifespan. That said, ideally, all these treatments would be available to everyone.*
> *Australian male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Making the procedure available to all would save the NHS money

Some suggested that it would ultimately be efficient and save public money to make the procedure available since the costs of ill health are borne largely by the state.

> *I think the principal of equal access to healthcare comes before ability to pay. This is preventative treatment which could save a lot of money later on. The NHS must be equipped to go beyond 'fire fighting' and look to future healthcare savings.*
> *British female non-parent, 55-64, graduate, genetic condition in family, genetically tested*

> *Should be paid for by the NHS, as in the long run it will save them money.*
> *British female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

One respondent said that this should be seen as an investment and also raised issues relating to access.

> *In an ideal world, treatments like this would be accessible to everyone with need. An argument could be made that it is in the government's interest to fund as the investment in preventing serious health conditions is cheaper than paying for life long treatments for many inherited conditions. Class disparity in who can access this technology further marginalises disadvantaged individuals - if they are now disproportionately having children with disability/medical issues, this costs them time, energy, money, emotional energy that will further the gap between rich and poor.*
> *Canadian female non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Infertility as a disease

One respondent noted that responses to this question might depend on views about whether fertility should be seen as a disease or not.

> *I really have a problem in deciding between option 1 and 2. Is infertility, or the impossibility to have a healthy child, a disease? If yes, then the procedure should be available for everyone. If no, then there is no reason for the public health system to pay for it. Of course, in this case rich people will have an advantage, but they already have many, so this additional possibility to have healthy babies would make no difference in the general order of things.*
> *Italian female non-parent, 35-44, postgraduate, no genetic condition in family, genetically tested*

Respondents who answered 'No, because the procedure should not be available to anyone'

Concerns about equality

In spite of responding this way, a number of those who did so raised equality related concerns in their comments.

> *Have you watched scifi-dystopias warning us of the dangers!!? It begins with celebrities endorsing, and then normalized, and then chaos filled of inequalities*
> *Filipino female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *Basic human decency and my egalitarian instincts*
> *British male non-parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

One respondent was concerned that such inequalities would result in a 'two-tier' society comprised of those who were and were not able to access the procedure.

> *This also creates a two tier society*
> *British female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

Concerns about safety and future generations

Issues relating to safety were raised once again.

> *As previously stated, the future of the human community as a whole takes precedence over the desires of any particular couple.*
> *American male non-parent, 65+, postgraduate, genetic condition in family, not genetically tested*

Though one respondent added that if concerns about risks could be addressed then it would be important for the state to provide access to the procedure to prevent equality related issues of the kind previously.

> *No, if it cannot ensure minimal risk. If this can be ensured, the public authorities should help people that cannot afford the procedure*
> *Argentinian female parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

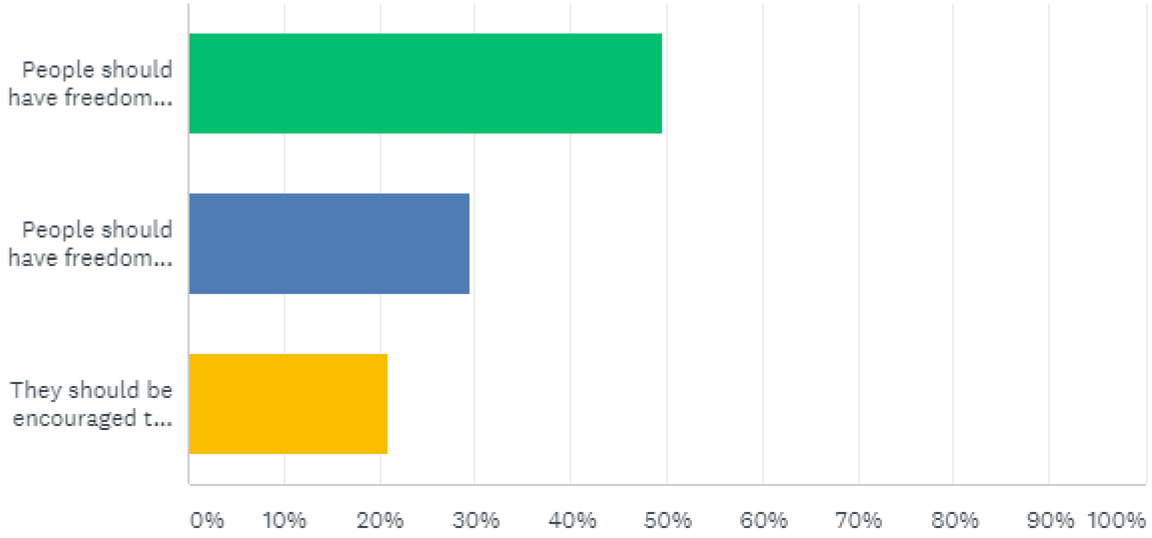
Benefits of not leaving the condition untreated

One respondent said that the condition should not be treated at all because this would mean that the condition would eventually disappear of its own accord.

> *Better to allow the genetic abnormality to die out of their blood line.*
> *Canadian female parent, 65+, graduate, no genetic condition in family, not genetically tested*

Question 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
140 of 282 respondents (49%)

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)
83 of 282 respondents (29%)

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
59 of 282 respondents (21%)

Respondents who answered ‘People should have freedom of choice and there should be no expectation that they should use the procedure’

Freedom of choice

A number of respondents reaffirmed in their comments the primacy of the value of individual choice in these circumstances. It was pointed out that prospective parents should be given adequate information about the procedure and the probably consequences of using it.

> *I believe all people should have the choice not to have treatment.*
> *British female parent, 55-64, postgraduate, not genetically tested no genetic condition in family*

> *I would support parents' freedom of choice, as long as they were sufficiently informed about the likely outcomes. I think it would be excessively restrictive to impose particular ways of having children, and what children people are permitted to have, especially as not all children are planned.*
> *British female non-parent, 18-24, postgraduate, not genetically tested, no genetic condition in family*

The idea that free choice should be the principle consideration in developing policy in this area was elaborated by respondents in different ways by respondents. Some said that this was important as prospective parents should be shown respect.

> *A couple deciding on the grounds of personal beliefs and values not to undertake the procedure should be shown due respect and not be penalised for holding to their beliefs.*
> *British male parent, 65+, postgraduate, not genetically tested, genetic condition in family*

Another respondent said that the prospective parents had a right to choose whether or not to use the treatment

> *Freedom of choice involves the right not to choose, which should be embedded in the terms of providing/offering whatever procedure. Informed consent ensures that the patients are aware of potentials benefits, as well as risks. Responsibility is by default accompanying freedom of choice.*
> *British female non-parent, 25-34, postgraduate, not genetically tested, no genetic condition in family*

Concerns about safety

A number of respondents said that because, in their views, there would be ongoing questions about the long term safety of the procedure, it would not be appropriate to encourage (or require) individuals to use it.

> *Again, back to safety. I do not believe this procedure is safe enough to say that everyone should be required to use it, because I do not accept the original value proposition...*
> *American male non-parent, 25-34, postgraduate, not genetically tested, genetic condition in family*

> *There's no guarantee of success and there are risks. Therefore choosing not to proceed is just as rational as choosing to proceed.*
> *Canadian male non-parent, 25-34, graduate, not genetically tested, genetic condition in family*

One respondent who took this view added that it was important that prospective parents were adequately counselled and supported.

> *There are risks involved in these procedures therefore it should be down to those individuals involved whether they want to go ahead with it or not, as with giving consent for medical procedures currently. These individuals should be given the appropriate counselling and support throughout their decision*
> *British female non-parent, 25-34, graduate, genetically tested, genetic condition in family*

Concerns about societal impacts

Some raised concerns about the broader impacts on society and implications for the ways in which disabled people might be valued or treated in a society in which this procedure was readily available

> *This kind of universalization of the procedure presents a very real and perilous moral risk of becoming non-mandatory, but socially expected, eugenics. A pressure can be eugenic, and can treat disabled people as a millstone rather than as full persons who are part of the social contract, even if it is not state-mandated. Nope nope nope nope. I will go to my grave noping that (not a technical term).*
> *American female parent, 35-44, postgraduate, not genetically tested, genetic condition in family*

> *We shouldn't value an individual less because of their medical condition or genetics.*
> *British female non-parent, 18-24, college educated, not genetically tested, no genetic condition in family*

> *I don't think people should be expected to use the procedure, but I also don't think the justification for this is freedom of choice. It seems reasonable that couples like this should have access to prenatal testing and termination if they are not in a position to raise a disabled child, and no pressure should be put on them either way. Of course raising a disabled child is significantly more resource intensive. But I think it's important to value and respect existing disabled children, just as I think it's more important to home existing children than it is to use technology to create more 'perfect' children. For me there is a strong distinction between existing children and embryos or foetuses.*
> *Australian female non-parent, 45-54, postgraduate, not genetically tested, no genetic condition in family*

One respondent elaborated on this point, claiming that society should not use genome editing to eliminate disability and suggesting that compassion and understanding to which disability can give rise is a good thing.

> *If people are happy to welcome an 'imperfect' child that is their choice. As a society we should not be seeking to eliminate all disability, disease and imperfection - these are what make us human. Dealing with our own suffering and that of others makes us more compassionate and understanding.*
> *British female parent, 45-54, postgraduate, not genetically tested, no genetic condition in family*

Possibility of religious objections

Some respondents pointed out that religious views held by some might mean that they would be morally opposed to use of the procedure. This, they suggested, might mean that it would not be fair to disapprove of those that did not make use of it.

> *There is always a cost to society, but what sort of society would we become if we didn't help those less fortunate than ourselves and we stopped helping. We have to take into account different religions and personal preferences.*
> *British female parent, 55-64, college educated, genetically tested, genetic condition in family*

> *Possible religious views of the parents.*
> *British female non-parent, 35-44, postgraduate, not genetically tested, no genetic condition in family*

Harmful effects of censure

Some respondents were worried that the experience the disapproval of society would be harmful for prospective parents and could make society less tolerant.

> *The censure by society of parents of such children will inevitably lead to reclusiveness and shame which will harm the individual in addition to harming the flexibility and tolerance of society as a whole.*
> *British female parent, 45-54, postgraduate, not genetically tested, genetic condition in family*

One respondent with similar concerns said that people like Chris and Dara might instead deserve praise rather than criticism

> *I am reminded of the stigma that parents face, when they give birth to a child who suffers from a genetic disorder after refusing to: undergo prenatal tests for such diseases / abort the foetus once the abnormality was detected / employ PGD in the first instance. Parents should not be condemned for bringing a child into the world, diseased or otherwise. In fact, this may be a brave and noble choice in a world that harbours prejudice to those who are disabled or different from the healthy "norm".*
> *Singaporean female non-parent, 18-24, graduate, not genetically tested, genetic condition in family*

No legal grounds for objection

One respondent argued that a child would have no cause for complaint if their parents had not used the procedure since if the procedure had been used they, the child, would not exist.

> *As seen recently in the UK courts, children cannot sue their parents for harms caused from their birth, since without those harms they would not exist as the individual that they are. The same principles apply here.*
> *British female non-parent, 18-24, graduate, not genetically tested, genetic condition in family*

Respondents who answered ‘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)’

Harm to the future child

A prominent theme amongst the comments of those that responded this way was the importance of the fact that harm that would be experienced by a future child if the procedure were not used. It was suggested by some respondents that the parents of this future child would bear some moral responsibility for this

> *They have the freedom to not do the procedure, but they must accept that they caused harm to a child*
> *American female non-parent, 18-24, postgraduate, not genetically tested, no genetic condition in family*

One respondent who felt this way said that parents who chose not to use the procedure for this reason should perhaps face some costs as a result.

> *This is very tough. My first preference was for freedom of choice. But if the probability of severe harm to the child is very high (say, greater than 30%) and costly to society, I can see a justification for Chris & Dara facing a possible cost. This is really a decision that should be made be a very well educated (in the issues under consideration) set of representatives drawn from the public (not politicians).*

> *Canadian American male parent, 65+, postgraduate, not genetically tested, no genetic condition in family*

Though another respondent who took a similar view nevertheless argued that this should not result in any financial costs to such parents since there are many other cases in which personal decisions about lifestyle and other things can give rise to medical need that is met by the state.

> *While I think Chris and Dara are well within their rights to refuse, I think some responsibility has to be accepted if the technique is not used and, subsequently, a child is born who suffers from a condition. I would be more inclined to press the responsibility for the harm rather than any cost to society, as we currently already pay significant amounts of money to treat the harm caused by lifestyle or other personal choices.*
> *British male non-parent, 25-34, postgraduate, not genetically tested, no genetic condition in family*

Possibility of justified reproof from the future child

A number of respondents alluded to what they thought would be the likely response of any future child about their parents' decision not to use the treatment.

> *More the cost to the unborn child - how would they feel knowing their parents could have opted for the procedure?*
> *Welsh female non-parent, 25-34, graduate, not genetically tested, no genetic condition in family*

> *This was a very difficult question to answer...but can you imagine what the child will say when they are older? "So you had the choice to have me healthy but you decided against it?" That would be heart breaking and I think a little cruel. On the other hand...this only applies if the procedure definitely, 100%, gets rid of the risk of the child getting the disease*
> *British female non-parent, 25-34, postgraduate, not genetically tested, no genetic condition in family*

One respondent who raised this point added that they thought that the parents would be morally responsible for the harm experience by their future child if they did not use the procedure.

> *My answer is really between the last two choices. They should absolutely be "encouraged" to use the treatment – by their doctor, presumably – since it provides substantial benefit and no harm. I would feel that if they chose not to get the treatment and their child was seriously ill as a result, they would be deeply morally culpable; their choice would be reprehensible. But they should nevertheless "have freedom of choice", and I would not agree that other factors "outweigh the parent's right to freedom to choose"; I think that right is pretty much absolute in such situations. I think the answers here are phrased poorly, actually; choices 2 and 3 overlap too much.*
> *American male non-parent, 45-54, postgraduate, not genetically tested, genetic condition in family*

Implications for state funded services

Some respondents raised points about the resulting costs for the NHS and claimed that parents who did not make use of an available procedure to prevent their child developing a serious condition should pay for the care that their child would need as a result.

> *If someone decides not to use it, they should pay the full cost of the resulting care and not have access to NHS funding for that condition.*

> *British female non-parent, 25-34, postgraduate, not genetically tested, genetic condition in family*

> *I have a problem with forced eugenics but equally it would be irresponsible of the couple not to take the opportunity and the State should not have to pick up the additional cost if they don't.*
> *British female non-parent, 45-54, postgraduate, genetically tested, genetic condition in family*

Concerns about societal impacts

Some respondents added caveats to their answers

> *This is always a difficult one. On the one hand I think the argument that people with disabilities and diseases are a 'burden to society' is deeply dehumanising and suggests (erroneously) that all disabled lives are not worth living and moreover that any person's value is measurable in terms of the work they do or the income they generate. On the other hand if I had a painful condition that could have been avoided I would probably prefer my parent's had used the technology, with the large caveat that I have no religious convictions about the 'givenness' of life or any kind of intentionality to the universe.*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

> *People should be free to choose, otherwise it devalues individuals with disabilities. But they would be aware of the life they are giving their child and if they can morally accept that, then that is okay. Otherwise you would be taking the approach of a eugenicist and banning people with disabilities from existence where possible.*
> *British female non-parent, 18-24, postgraduate, not genetically tested, no genetic condition in family*

Prospective parents in this situation should not have children

One respondent said that prospective couples with risk of having a child with a serious inherited condition of this kind should be encouraged not to have children.

> *They should be encouraged to adopt instead of breed*
> *Demographic data not provided*

Respondents who answered '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'

Harm to the future child

Respondents answering this way made comments about likely harms to the future child and the importance of the child's welfare.

> *The child's welfare outweighs the parents' personal or religious beliefs.*
> *British male non-parent, 35-44, postgraduate, not genetically tested, no genetic condition in family*

> *This is a tricky one... Autonomy is important, but so is safeguarding the child. I lean towards encouraging treatment as although I understand people with disabilities bring positive things to society, not encouraging people to use the treatment seems similar to harming the child to produce disability intentionally. This is based on an assumption that the condition is more likely than not. If we are talking 3-5% chance then I would lean more towards the parents having the choice.*
> *Australian male non-parent, 25-34, postgraduate, not genetically tested, no genetic condition in family*

This point was made strongly by some respondents who suggested that parents who did not use the procedure would be morally responsible for the harm their child would experience.

> *Couples should be informed how miserable they would make their child's life if they pass on a genetic condition they knew about.*
> *Bulgarian female non-parent, 18-24, graduate, not genetically tested, genetic condition in family*

> *Unacceptable to wilfully have disabled children, unless such disability confers proportional benefits*
> *British male non-parent, 35-44, postgraduate, genetically tested, genetic condition in family*

Use of the procedure should not be forced

A number of those that wanted to see use of the procedure encouraged used their comments to clarify that they thought that prospective parents should nevertheless not be forced to use it.

> *Encouraged is the key word. Not forced. Someone said "If you have the ability to do good, and choose not to, that is the morally indefensible position."*
> *British male non-parent, 55-64, graduate, not genetically tested, no genetic condition in family*

> *If "encouragement" is not coercive, I am fine with encouragement. There are costs (in terms of well-being) in infringing on parental freedom, but in this case they may be ought weighed by the gains. Anyway, coercion is a matter of degree: there is a certain level of coercion such as the gains are no longer enough.*
> *British female non-parent, 25-34, graduate, not genetically tested, no genetic condition in family*

One respondent added that there should similarly be no penalties for not using the procedure.

> *Encouragement, but definitely neither compulsion, nor penalty, if they choose not to.*
> *British male parent, 55-64, postgraduate, not genetically tested, genetic condition in family*

Impact on state funded services

The implications for public resources in terms of medical and other costs were raised by some respondents.

> *My opinion is wavering for this question. They should be encouraged but not forced. I think the autonomy of the parents as well as that of the future child should be balanced. If the parents choose not to go ahead with the treatment I don't think society should have to bear downstream medical costs, but nor should the child….*
> *Australian male parent, 55-64, postgraduate, not genetically tested, genetic condition in family*

> *My first thoughts before reading your possible answers were: selfishness and cost to society.*
> *French British female non-parent, 45-54, postgraduate, not genetically tested, no genetic condition in family*

Scenario 3

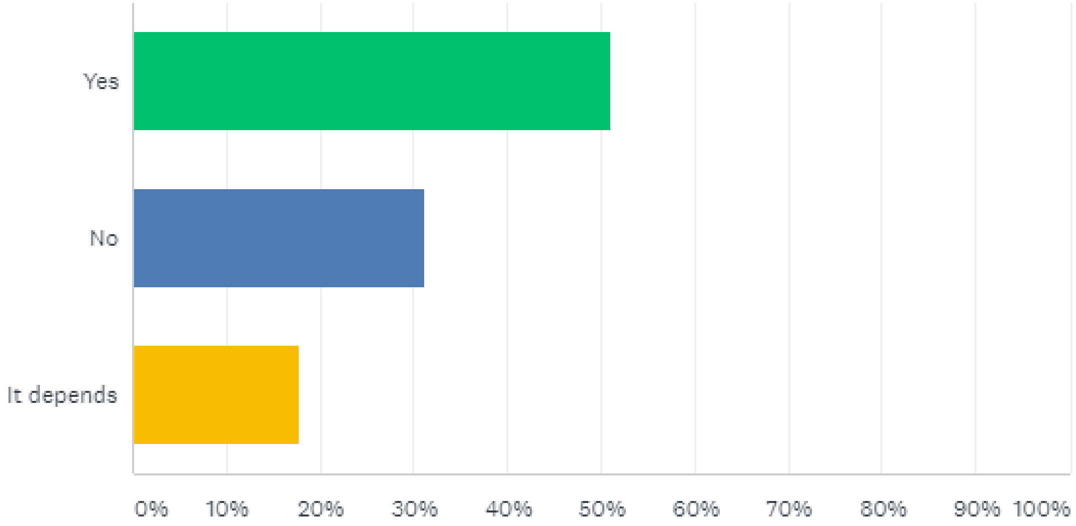
Eli and Franc live and work in an area with endemic infectious disease that is often fatal, especially in infancy.

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

There is a rare genetic mutation that confers a high level of resistance to the disease. Using genome editing, this mutation 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 altered so that their children will be born resistant to the disease.

Question 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
149 of 292 respondents (51%)

No
91 of 292 respondents (31%)

It depends
52 of 292 respondents (18%)

Respondents who answered ‘Yes’

Individual freedom and privacy

Some respondents said in their comments that Eli and Franc should be free to choose to use the procedure since it stood to affect them alone

> *As with the other two scenarios: basic freedom, consenting and informed adults, no third parties harmed.*
> *American male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

Two respondents who answered this way mentioned privacy specifically

> *The couple's decision is private and does not carry public risk.*
> *American male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *Procreative freedom and right to privacy*
> *American female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Public health issues

Some respondents pointed out that in addition to the advantages that would be experienced by Eli and Franc’s future child if they were to use the procedure there would also be benefits to the wider public in reducing the risk of, or slowing, the spread of the disease

> *Eliminating infectious disease is a public good.*
> *American female non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *The procedure will increase their child's chance of survival and will also contribute to herd immunity, reducing the spread of the disease and benefitting other people too, similarly to the case of vaccines.*
> *British male non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested*

> *If it helps reduce the spread of the disease during an outbreak.*
> *British female parent, 55-64, college educated, genetic condition in family, genetically tested*

Similarity to vaccinations

Some respondents said that use of the procedure would resemble vaccinating a child and suggested that the two were morally equivalent

> *Not much different to receiving a vaccine, nothing unethical about making someone immune to a disease.*
> *Demographic data not provided*

> *This is very clear case of a medical procedure preventing the likelihood of death through disease. This is, ultimately, no different from preemptive vaccination.*
> *British female parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Responsibility to use the procedure

Some respondents thought that Eli and Franc had a duty to use the procedure to prevent the harm that may otherwise be experienced by their child.

> *It is the only moral option.*
> *Czech male non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *It is child abuse to bring a defective child into the world when you could have prevented it*
> *American male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

Public resource considerations and fairness

Some respondents suggested that if Eli and Franc were to use the procedure then this would mean that their child would have an unfair advantage in that she or he would have health benefits that other children living in the region would not have

> […]*It seems like the sort of thing that should be on offer to most people in this region. That raises justice concerns of the sort raised in the previous 2 scenarios.*
> *American female parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

One respondent who raised this issue added that there might nevertheless be differences in the short and long term implications of use of the procedure for social justice.

> *This seems to cross the line from repairing a disease to giving an advantage. While this may be detrimental to equality in this area I think it aids equality on a larger scale.*
> *Australian male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Interaction with evolutionary processes

Some respondents used their comments to express views about how use of the procedure might interact with evolutionary processes. One respondent said that the benefits that the procedure would confer on future people were ones that evolution would select for anyway, suggesting that use of the procedure would quicken changes that would have otherwise happened ‘naturally’.

> *Accelerator for evolution, this happens anyway*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

Another respondent however suggested that use of the procedure might work against or undermine evolutionary processes and that those children born from embryos that had undergone the procedure might be vulnerable to other diseases or experience greater suffering in virtue of living longer than they otherwise would have.

> *That said, I am aware there are arguments that if less people died, those who survived may not have the resources to live on. Complex arguments around "survival of the fittest" clearly also come into play, as it is possible that those individuals, spared one disease, may be susceptible to many others, or may live longer but less fulfilled lives/lives with more suffering due to their resistance to disease being greater than the longevity of e.g. cognitive functioning/joint health etc*
> *British female non-parent, 35-44, graduate, no genetic condition in family, not genetically tested*

If the environmental problems could not be addressed

One respondent suggested that whilst Eli and Franc should be able to access the procedure it would be preferable to aim to reduce the prevalence of the disease in the region

> *Honestly, I think it would be better to fix the environmental problem. I would put all my resources in that, rather than in gene editing. But if to fix the environmental problem was really impossible, then yes, they should be able to use the treatment.*
> *Italian female non-parent, 35-44, postgraduate, no genetic condition in family, genetically tested*

Respondents who answered 'No'

Uncertainty about long term consequences

Many respondents raised concerns about safety of the procedure given the current limitations in understanding of the long term effects of making genetic alterations to human beings.

> *If we're talking about the present day and the provisions for managing unknown risks that might arise, then the answer should be negative.*
> *Canadian American male parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

> *Long term effects cannot be known*
> *British male non-parent, 18-24, graduate, no genetic condition in family, not genetically tested*

The possibility that the modification of a particular targeted trait might result in additional, unpredicted changes to other traits was raised.

> *Don't know what other effects tampering will produce*
> *British female parent, 25-34, graduate, genetic condition in family, not genetically tested*

And the possibility that the altered gene might have other, beneficial functions that would be lost also raised.

> *Our knowledge of the genome is limited. Maybe the resistance variant has other consequences. Research should rather focus on how to limit the disease spread and for everyone to have equal access to health care.*
> *German non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Fixing the environmental problem would be preferable

A number of respondents said that implementing policies to reduce the spread of disease, such as vaccination, was preferable to genetically altering embryos to produce disease resistant people.

> *Instead of focusing on the making people more resistant to infectious disease, we should be focusing on why there are such rates in the community and procedures on how to decrease the rates of the disease that doesn't have to do with tinkering with the genetics of children. Also this is could be extremely dangerous...what if altering this gene ended up with other unforeseen consequences.*
> *American female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *This is about infectious disease, which is not a certainty but a possibility. It is best to not fiddle with nature and instead try to avoid infection in the first place, as society does with a great many infectious diseases already (e.g. vaccination).*
> *British male non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *Really? Help! "Benefit from immunity" ?? You are promoting the use of genetic engineering instead of public health interventions, such as vaccination, and occupational hazard intervention. ???*
> *American female parent, 55-64, postgraduate, genetic condition in family, genetically tested*

Public resource considerations and fairness

Some respondents said that unless all prospective parents in the region were given the opportunity to use the procedure it would not be fair for Eli and Franc to use their superior wealth

> *Unless the procedure were to be universally available through public funding, it would be hugely unfair to allow those well off enough to afford it a huge advantage that is not available to others.*
> *British female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *Creates unfairness.*
> *British female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

One respondent added that this strategy might fail because the disease would adapt.

> *Because diseases adapt. We also have to ask why there isn't sufficient health care in the region. If the state is failing to protect its people from disease then this will only favour the rich.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

The procedure would be an enhancement rather than a medical treatment

Some respondents said that the procedure would not constitute a medical treatment, or was not targeted at existing harms.

> *This is not seeking to remove an existing harm; this is seeking protection against a potential one (an 'improvement'). I think as a species we should try to avoid genetic 'improvement' due to its immense potential for harm by creating 'genetically second class humans', should such 'improvements' become the norm.*
> *British female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *Editing the embryos such that the resulting children benefit from immunity to the disease amounts to an enhancement, rather than a treatment of an underlying condition. As a matter of principle, enhancements are far more drastic than treatments, and do not cross the threshold of permissibility…*
> *Singaporean female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

Consent

One respondent raised consent, amongst a range of other issues, suggesting that the fact that Eli and Franc's future child could not agree to undergo procedure made it problematic.

> *Germ line editing is unethical because of the issue of consent, risks harm because of the risks of unintended collateral genetic mutations, and as yet has insufficient medical evidence base. In this hypothetical scenario, the ethical objection would still stand and the unknown risk should still be considered relevant.*
> *British male parent, 65+, postgraduate, genetic condition in family, not genetically tested*

Diversion of resources from research

Some respondents raised the possibility that use of the procedure might mean that there were fewer incentives for research into the disease itself.

> *It would also draw resources from research to stop the disease, which is more desirable […]*
> *British female parent, 65+, graduate, no genetic condition in family, not genetically tested*

> *Not if this removes funds from trying to tackle the disease itself or for preventative measures e.g. early vaccine. I don't think this is a strong enough scenario to justify the risk. All other options should be considered first. You are now intervening with a potentially healthy embryo not one identified as at a definitive genetic risk.*
> *British male non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

Respondents who answered 'It depends'

Uncertainty about long-term consequences

Points about the safety of the procedure, and the possibility that the edited gene might have poorly understood, positive effects was raised.

> *This again raises the question of genetic diversity. Eliminating bad teeth may destroy other essential characteristics in the human population. Regulatory changes are notoriously hard to disentangle.*
> *New Zealand male parent, 65+, postgraduate, genetic condition in family, genetically tested*

Some respondents pointed out that the risks attached to undergoing the procedure might be greater than those of catching the disease.

> *The risks of the procedure may outweigh the risks of catching the disease.*
> *British female parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

> *Which risk is bigger, that the kid will get the infectious disease versus the risk of the procedure?*
> *Austrian female non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

Availability of medical treatments for the condition

Some respondents suggested that the availability of alternative means of avoiding having the disease was relevant.

> *… Are there other measures to prevent contracting the disease?*
> *British French male non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

And another respondent said that if the disease was not treatable then use of the procedure might be permissible

> *Depends on whether a treatment exists for the condition or not. If no treatment exists - then may be acceptable….*
> *British male parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

Access and social justice issues

Some respondents raised issues relating to access and fairness and said that Eli and Franc should be able to use the procedure only if it were available to others.

> *If all couples in the area were offered the same choice then it may be acceptable.*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

One respondent pointed out that efforts to tackle the disease in other ways might lessen in the event that the children of wealthy parents were immune to it

> *It depends if the procedure is available to all couples where they live. If it is only available to wealthy couples I would have concerns that once wealthy children were mostly resistant, efforts to combat the disease through other methods would be a lower priority for government healthcare spending.*
> *British female non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

A combination of factors are relevant

Some respondents suggested that a wide range of issues, including access, cost, likely success and availability of other options were relevant to the question of whether Eli and Frank should be able to use the procedure.

> *Lots of unknowns here - including how much the disease itself mutates and whether the acquired immunity will work in the long term. Also is the procedure available to everyone, and what are the costs and benefits of doing this versus finding a way of eradicating the disease.*
> *British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

One respondent suggested that it was difficult to respond without further information.

> *What studies have been done to consider what effects changing this gene might have at the population level? Is this procedure available to all/how expensive is this procedure? Are there other measures to prevent contracting the disease? Can we ensure that only the gene responsible for a greater propensity to contracting the disease will be modified through this procedure? What effects will this gene have should the child survive to adulthood?*
> *British French female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

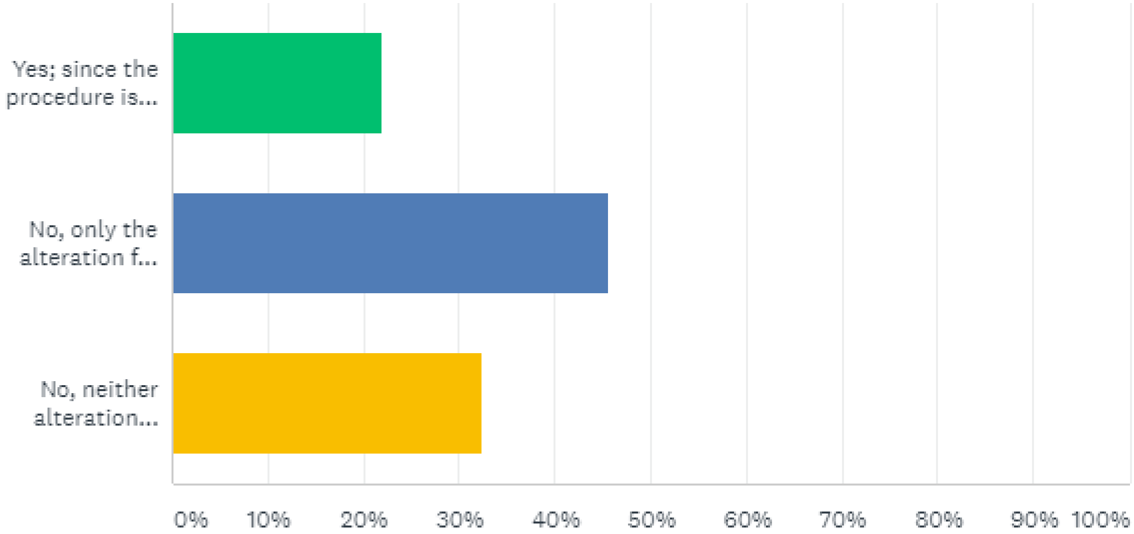
Eugenics

Worries about the procedure initiating eugenic practices were expressed.

> *This sits a little uncomfortably for me. This is heading toward eugenics and an alteration in this scenario almost seems cosmetic as taking precautions are effective.*
> *British male non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

Question 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



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
64 of 290 respondents (22%)

No, only the alteration for disease resistance should be permitted
132 of 290 respondents (46%)

No, neither alteration should be permitted
94 of 290 respondents (32%)

Respondents who answered ‘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’

Reproductive freedom and privacy

Some respondents expressed the view that Eli and Franc are entitled to make their own personal or private decisions about use of this procedure

> *Eli and Franc are morally permitted to do whatever they like with their bodies and genetic material.*
> *American male non-parent, 25-34, postgraduate, genetic condition in family, genetically tested*

> *The couple's decision is private and does not carry public risk.*
> *American male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *This falls under the reproductive freedom category.*
> *British male non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

One respondent who thought that individual freedom was the principal consideration nevertheless stated that this scenario seemed different in some ways to those described in earlier survey questions.

> *This is the first one that gave me pause, since it is entirely optional (i.e., not to alleviate medical issues) and would presumably be heritable. I don't think it's a good idea for the human race to start altering itself arbitrarily until we have a much, much better understanding of what we're doing; with a fuller understanding, I would have no objection, though, as this is not a fundamental moral objection so much as a concern about long-term risk. But in the end, I think this still comes down to basic freedom, and yes, they should be allowed to do it. I would try to talk them out of it, though.*
> *American male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

There would be benefits to the future child

Some respondents said they thought use of the procedure would be acceptable because it would bring benefits to the future child, in view of the superior quality of life or happiness they would get from their musical ability, or the improved relationship they might consequently have with their music-loving parents.

> *Anything that makes people happier is not only morally acceptable but morally required given the unethical decision to create a child.*
> *American female non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

> *Here we leave dire health concerns to cosmetics. However, quality of life is extremely important, just under health and freedom. I would like to do this very thing myself, alter my genes, or interface with technology for high order skills, particularly singing and music. I am writing a story where the main character alters her voice with technology.*
> *American male parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *The musical ability gene confers an objective benefit to the child, and if they are genetically inclined to share their parents' interests, they are more likely to have a better relationship. At the same time, there may be a risk that the genetic diversity of the population will be compromised if this modification becomes widespread. As*

> *such, it may be that there should be limitations on the number of such modifications made.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Use of the procedure resembles behavioural parental interventions

Some respondents used their comments to draw attention to the fact that parents already intervene in their children's lives to encourage musical ability. It was suggested that altering a future child's genes so that she or he had musical ability was morally equivalent to arranging music lessons.

> *No difference with piano classes etc. here I even doubt the """musical ability""" variant would even be bad pleiotropically, so sure.*
> *British male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *There is little difference between parents encouraging a child with a desired skill to use it (e.g. Andy Murray's upbringing) and trying to produce "soft" changes in the genome.*
> *British male parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

Concerns about societal impacts

Some respondents raised issues concerning the potential societal implications of use of the procedure. One respondent said that such consequences should be weighed more prominently in cases that did not involve health.

> *In general, considerations regarding societal consequences are relatively more important in non-medical cases (e.g. suppose musical ability was particularly important for success in this hypothetical scenario), but also if there were unwanted consequences, prohibitions of the procedure would not be the only option (notice also that the distinction between medical and non-medical is far from sharp or stable).*
> *Italian male parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

One respondent made this point acknowledging simultaneously that use of the procedure would probably give rise to tangible benefits for Eli and Franc's future child

> *The musical ability gene confers an objective benefit to the child, and if they are genetically inclined to share their parents' interests, they are more likely to have a better relationship. At the same time, there may be a risk that the genetic diversity of the population will be compromised if this modification becomes widespread. As such, it may be that there should be limitations on the number of such modifications made.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Respondents who answered 'No, only the alteration for disease resistance should be permitted'

Autonomy of the future child

Some respondents used their comments to express the view that children should be able to make their own autonomous choices about issues like music

> *…The child's autonomy…*
> *Australian male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*
>
> *Musical ability is a choice best left to the individual, not forced on one by the parents. Such ability is not necessary for a fulfilling life.*
> *British male non-parent, 65+, college educated, genetic condition in family, genetically tested*

Some of those making this kind of point expressed doubt that prospective parents should be able to impose their own personal preferences onto the characters of their children.

> *….Personal preferences, such as music, should never be the right of parents to impose on their children. Parents should definitely not be allowed to determine personal tastes of children genetically.*
> *British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*
>
> *I do not think it is appropriate for parents to have this level of influence over their child - even with the hypothetical musical ability gene, the child may have little interest in music. It seems analogous to choosing to have a child of a specific gender due to expectations of the child's characteristics in keeping with gender norms (which I would also not support).*
> *British female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

No health benefits

Some respondents objected to the use of the procedure for this purpose since the changes would be 'cosmetic' or 'aesthetic' and would not bring any advantages for health.

> *I believe it's unethical to alter for something that is almost cosmetic I.e. not beneficial to health and wellbeing*
> *Demographic data not provided*
>
> *Medical benefit only, not aesthetics.*
> *British male non-parent, 18-24, college educated, no genetic condition in family, genetically tested*
>
> *Cosmetic enhancements shouldn't be allowed as it is then only a short step to designer babies. No parent should expect their offspring to enjoy the same things as they do - children are individuals and should be able to choose to hate music! This sort of change would place unrealistic and unfair expectations on the child throughout their life.*
> *British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

Some of these respondents made references to 'designer babies'

> *This is now heading down the road towards "designer babies". Prevention of disability or disease is one thing, breeding children for specific traits quite another.*
> *British male parent, 65+, graduate, genetic condition in family, genetically tested*
>
> *It's creating the designer babies, therefore no. Should such child be allowed to win in musical competitions not because he practiced, but because his mum and dad paid/decided for him to be born like this?*
> *Russian female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

Safety and uncertainty of long-term consequences

Respondents raised concerns about safety and long-term consequences once again; in particular, the possibility of there being unforeseen adverse consequences of making apparently positive modifications was raised.

> *Altering genetic code carries risks and it should only be used for medical reasons*
> *Italian female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *It is not an absolute no - but depends as I mentioned on long term consequences of altering the DNA. This would be unpredictable. Hence the risk:benefit ratio would not be favourable within the constraints of our current knowledge. If our knowledge of genetic changes and future consequences improve markedly, the question could then be debated again. .*
> *British male parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

Concerns about societal impacts

One respondent said that it was important to pursue diversity and equality in society and called for public discussion of where boundaries for use of such procedures should be. Eugenics and designer babies were raised as concerns.

> *I believe a diverse society is a strong one and that leaving traits like musical ability and scientific ability to chance maintains diversity, the child's autonomy and a society's equality.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

> *Designer humans, designer soldiers, this is fairly abhorrent to me. Besides, however much musical talent the child has, that child may not want to play music. This will be forcing the child down a path not of its own choosing. ie re moving free choice.*
> *British female parent, 65+, graduate, no genetic condition in family, genetically tested*

> *We need to discuss boundaries as a society for ensuring a balance between the prevention of disease against the "slippery slope of eugenics" ... Again difficult to answer in a sentence!*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Respondents who answered ‘No, neither alteration should be permitted’

Concerns about eugenics

A number of respondents raised worries about eugenics.

> *The idea of altering the human genome for certain traits or skills is disturbing. Reminds me of Nazi experimentation in WWII and the eugenics movement that proceeded it (which I believe had a large base in the UK).*
> *Australian female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *This makes the point about the "slippery slope". Eugenics is not permitted and should never be.*
> *British male parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

> *This is completely unnecessary and strays into eugenics. […]*
> British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested

One respondent added that this would entrench inequalities and commodify children.

> *This is the consumer eugenics scenario. This will be socially disastrous because it would massively exacerbate social inequality, allow social prejudices to determine which children get born and turn human beings into designed objects/commodities.*
> British male parent, 55-64, postgraduate, genetic condition in family, genetically tested

Autonomy of the future child

Some respondents said that prospective parents should not be able to intervene to alter personality of their future child on the basis of their own personal preferences,

> *I do not believe parents should be allowed to act on such whims. A child should have the right to develop as an individual, not as the fantasy of their parents. I would actually be concerned about Eli and Franc's psychological state and wonder about their suitability to be responsible parents.*
> British 25-34, non-parent, 25-34, graduate, no genetic condition in family, not genetically tested

> *You should not be allowed to alter the personality of a child or any other human. That is one thing that is purely theirs and their own decision. And the risks would not be likely to outweigh the benefit.*
> British female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested

One respondent said that a future child had a right to genetic identity that had not been tampered with.

> *Editing the embryos to enhance them is a far more drastic measure than treating an embryo for an underlying genetic disease. This is cannot cross the threshold of permissibility, since there is a high threshold to be crossed before parents' procreative autonomy can outweigh the child's right to untampered genetic identity.*
> Singaporean female non-parent, 18-24, postgraduate, genetic condition in family, not genetically tested

Uncertainty about long-term consequences

Respondents raised issues relating to the safety of the procedure. Concerns that genes that were edited or introduced might have effects that were unanticipated were raised once again.

> *Whilst a genetic variant might be 'associated' with musical ability... it may also combine with other specific variants not associated in the same study, that are held by those individuals to prevent deafness... for example…so by altering this one genetic variant, without the other unidentified variant, they could simply produce deaf children...*
> British male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested

Safety concerns were more pressing in the example, one respondent said, since musical ability was not in their view a necessary trait

> *There is a big difference if the genetic lottery makes it impossible to have children at all, or one ends up with a child who is doomed to a horrible end because of a genetic flaw. But beyond that, the consequences are unpredictable and no-one could say for certain what that child might lose in the modification. Dealing with*

> *adversity is a key human skill and many characteristics that seem undesirable in one context can be advantageous in another. In cases like this, the whole set of outcomes is not knowable, and the benefits are not so evident--one can live without music.*
> *British female parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

Concerns about designer babies

Concerns about designer babies were raised

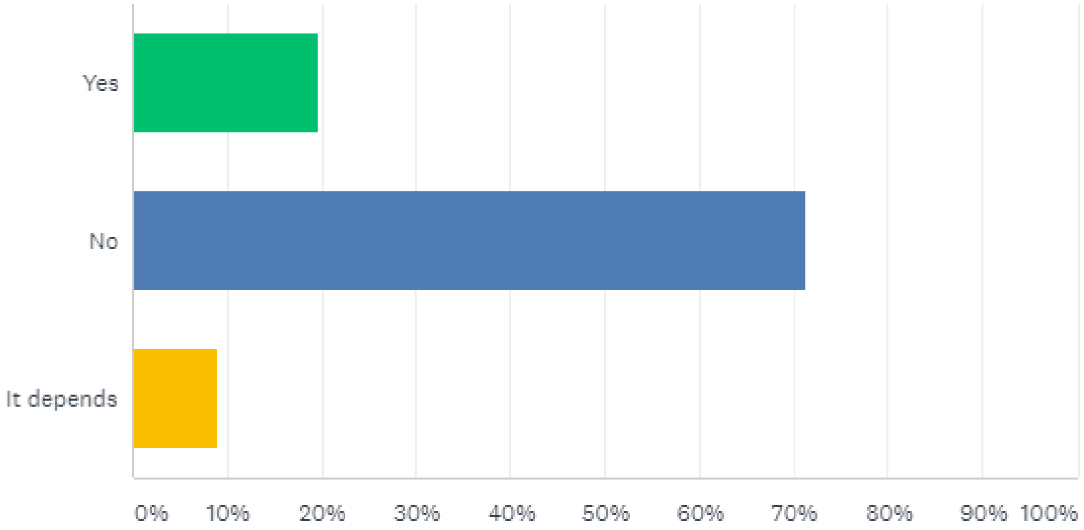
> *This comes dangerously close to 'designer babies' and should not be allowed.*
> *British female parent, 45-54, college educated, genetic condition in family, genetically tested*

One respondent said that the procedure would produce children that were not human.

> *Disaster. Designer babies. No longer quite human beings.*
> *British female parent, 25-34, graduate, genetic condition in family, not genetically tested*

Question 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?



Yes
57 of 290 respondents (20%)

No
207 of 290 respondents (70%)

It Depends
26 of 290 respondents (9%)

Respondents who answered ‘Yes’

Use of such procedures would benefit the human species

Some respondents said in their comments that they thought that Eli and Franc should be able to use this procedure to produce a child with exceptional intelligence since children with this feature would benefit the human species.

> *Increased intelligence is something we as a species should be striving for. We need to move the species forward, and this is one of the areas we should focus on, whether through genetics or other means.*
> *British male non-parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

> *For the sake of all humanity.*
> *Czech male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

One respondent who made the point that such a child would benefit society added that the procedure should be available to everyone

> *A more intelligent child could, like a more musically gifted child, contribute more to humanity and society, as well as leading a happier life (probably), which can't be a bad thing. Once again, this must be available to all to make it ethical, otherwise only those who can afford it will have access to it and slowly but surely the wealthy elite will transform their children into a genetically superior "master race".*
> *British male non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested*

Reproductive freedom and privacy

Points about the personal freedoms of Eli and Franc and the privacy of decisions about reproduction were raised by some respondents.

> *Eli and Franc are morally permitted to do whatever they like with their bodies and genetic material.*
> *American male non-parent, 25-34, postgraduate, genetic condition in family, genetically tested*

> *The couple's decision is private. Having intelligent children may have downsides, but it is within the rights of parents to choose this.*
> *American male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

It would be on a par with choosing an intelligent partner

It was suggested by some respondents that this kind of selection already happens in that individuals may select partners on the basis of their intelligence in order to have a more intelligent child.

> *We already perform a type of selection when we choose a spouse. This is simply more efficient.*
> *American female non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *We already allow mate selection on the basis of intelligence i.e the selection of any genes that might influence that. Why be inconsistent?*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

It would be wrong not to use the procedure

Some respondents made the above claims more strongly, claiming that prospective parents had duties to use the procedure, for the good of the future child.

> *It is child abuse to bring a weakened child into the world when you could have prevented it.*
> *British male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *This ought to be mandatory, for roughly the same reasons I cannot feed schoolchildren lead.*
> *American male non-parent, 18-24, postgraduate, genetic condition in family, not genetically tested*

Concerns about societal impacts

Some respondents added caveats relating to potential downsides of letting people access the procedure.

> *In this case considerations regarding societal consequences are even more important than in the case above. There are benefits in having highly intelligent people, but also important costs (if these people are already advantaged or tend to be assholes, or in fact both). Prohibition might be in some cases the best option, for instance if it is less costly than any alternative, but there is no in principle reason that genetic interventions of this kind should be prohibited.*
> *British male parent, 25-34, doctorate, no genetic condition in family, not genetically tested*

> *I realize the serious social implications to designer babies, and it's associations with eugenics. but if I could insure my child, or myself, elevated intelligence, I certainly would, even after considering the risks, I would. becoming a serious contribution to humanity is a life worth living.*
> *America male parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Benefits to the future child

Some respondents highlighted the advantages that would be experience by Eli and Franc’s child, if they were to use the procedure for this reason

> All else being equal, smarter is better for Eli & Franc's offspring and the world.
> *British male non-parent, 25-34, college educated, no genetic condition in family, not genetically tested*

Respondents who answered ‘No’

No guaranteed benefits to the future child

A number of respondents pointed out that exceptional intelligence would not necessarily improve the welfare of a child that had that feature.

> *There is no guarantee that having an exceptionally intelligent child will give that child a better quality of life.*
> *British, does not identify as male or female, non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *Intelligence doesn't equal happiness. I'd probably endorse gene editing to ensure happiness?!*
> *Welsh female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

Some respondents made more specific claims challenging the idea that exceptional intelligence would be beneficial, citing social skills, good citizenship and compassion as valuable traits not always linked with intelligence.

> *Comes to consideration of long term views about eugenics and a super race. Believe that it is OK to make changes for health reasons but that is where it stops. We need more than the super intelligent for a caring and compassionate society….*
> *Scottish female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

> *As a member of a high IQ society, my experience is that exceptional intelligence rarely seems to be linked with great social skills. Indeed it may be that those with poor social skills spend more time studying, and therefore are better at passing intelligence tests. There is not guarantee that selecting for "exceptional intelligence" may not result in the selecting out of another desirable trait.*
> *British male parent, 65+, graduate, genetic condition in family, genetically tested*

> *More genetic determinism, not grounded in reality. Intelligent people are not necessarily better citizens, well-adjusted or happy. IQ is a social construct.*
> *Australian male non-parent, 65+, postgraduate, genetic condition in family, not genetically tested*

Access and social justice issues

It was suggested that use of the procedure by Eli and Franc would give their child unfair advantages over others.

> *It is not life threatening and may give their child an unfair advantage in the future*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *See above, everybody would want to have the same high quality traits, the risk would be a split in a few generations, between the improved humans and the "normal" ones.*
> *British French female non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *It is a more difficult case and I am not entirely sure of my response but I have replied no because it would put some individuals in an unfair advantage over others on purpose and it would expose them to unnecessary risk…*
> *Italian female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *A market would rapidly develop for wealthy parents to be and the gap between rich and poor would rapidly widen*
> *Australian female non-parent, 45-54, doctorate, no genetic condition in family, not genetically tested*

No health benefits

Some respondents objected to use of the procedure on the grounds that the alteration would confer no medical or health benefits on the future child. Some said that the procedure should only be used to prevent disease.

> *Genes should only be modified for medical reasons, e.g. preventing disease, rather than cultural or social preferences.*

> *British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*
>
> *Potential for biological classes, treatment should only be used for disease prevention*
> *Welsh female non-parent, 18-24, college educated, no genetic condition in family, genetically tested*

Another respondent said that alterations should only be made in cases where these would prevent a 'seriously debilitating' condition.

> *Again, only interventions for conditions that would be seriously debilitating to the child's life to the point of harm should be considered...*
> *British French female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

Diversity

Issues relating to diversity, in different contexts, were raised. One respondent suggested that making genetic modifications to people to increase intelligence might compromise the broader success or health of wider population in homogenising the gene pool.

> *Again this is not a simple question of survival; we cannot apply a value to different levels of intelligence as a diverse gene pool is ultimately desirable.*
> *British female non-parent, 18-24, college educated, no genetic condition in family, not genetically tested*

Another respondent said that diversity had another kind of value, claiming that this made the human race interesting and robust

> *Again this is different to preventing disease. If we start to engineer humans in this way I worry that we will move toward uniformity and start to eliminate diversity which makes humans interesting. Diversity in a population is what makes us robust*
> *Canadian female non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

It would be better to improve education

Some respondents argued that alternative means of increasing intelligence, such as greater resources for education, were preferable to genetic modification

> *This wouldn't be preventing an inherited illness or life limiting condition. For me the money would be better spent on improving the education system for the benefit of a whole generation of children rather than benefitting one individual.*
> *British female parent, 55-64, graduateelors, genetic condition in family, genetically tested*
>
> *Spend the money on some books for the child to read.*
> *British male non-parent, 18-24, graduateelors, no genetic condition in family, not genetically tested*

Autonomy of future child and extent of parental freedoms

Issues relating to the extent of parental freedoms to alter their children were raised.

> *You shouldn't be able to define how you want your child to turn out. Intelligence and/or musical ability does not necessarily mean the person will be successful and should be up to the child to determine what they do with their futures. the ability to resist disease will enable them to have a future, whatever they decide to do with it.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

One respondent expressed this as a concern about designer babies

> *As with my previous answer, this is a designer baby concept and intellect should be selected for.*
> *British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

Concerns about future uses

Some respondents were concerned that this use of the procedure would lead to other uses that would favour characteristics.

> *As above improvement engineering should not be allowed. The end of this would be designing soldiers with excellent night vision and high propensity toward obedience. Generally creating a Frankenstein's monsters from whatever the government of the day decided were desirable traits*
> *British female parent, 45-54, graduate, genetic condition in family, genetically tested*

> *Arms race to make better, tougher, more aggressive people*
> *British male parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Unrealistic scenario

It was also suggested that the described scenario was not realistic.

> *This question should not even be asked, given that it is highly unlikely that complex abilities are due to the possession of a given gene or genes.*
> *American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested.*

> *This is also daft*
> *British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested.*

Respondents who answered ‘It Depends’

Concerns about societal impacts

The societal implications of use of the procedure for this reason was raised by some respondents

> *Very very unsure of the social and economic implications of this type of thing.*
> *British male non-parent, 25-34, graduate, genetic condition in family, genetically tested*

> *How widely available is it? This could have social ramifications we need to consider.*
> *American male parent, 25-34, graduate, no genetic condition in family, not genetically tested*

Some of those with these concerns expressed worry that a social divide might spring up between those who had and had not been modified with the procedure

> *….Again I wonder if there are concerns regarding social justice (depending on the expense of utilising such procedures) and wonder what impact the ability to choose such a trait would have on society (particularly on people who had not had this trait chosen for them, and on prospective parents who have to decide whether to choose such a trait).*
> *British male non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *What is the context? Can everyone become more intelligent if they want to? Will this create a social divide? Is the planet so broken we need people with exceptional intelligence to solve problems?*
> *British female non-parent, 35-44, graduate, no genetic condition in family, not genetically tested*

If there is equal access

Relatedly, some respondents said that the procedure might be acceptable only if everyone had access to it.

> *Depends on if it is being allowed elsewhere. If other people are allowed to "boost" their children's intelligence, then the couple should be allowed to as well.*
> *British male parent, 25-34, postgraduate, genetic condition in family, genetically tested*

> *If the procedure was available to everyone.*
> *Turkish male non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested*

One respondent said that

> *…If such treatments are available only to the rich, a caste system may emerge. As such, they should be provided free of charge to everyone else, as well, subject to the restrictions I have already mentioned.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Potential for benefits to the human species as a whole

The possibility that the procedure might benefit the human species as a whole, in virtue of increasing the overall amount of intelligence in the human population, was raised by some respondents

> *This is not a frivolous desire and to be honest we can do with a bit more intelligence around the place. But what might it lead to having set a precedent?*
> *British female non-parent, 45-54, postgraduate, genetic condition in family, genetically tested*

> *It still seems like the child may be a thing to increase the parents standing, rather than an entity in its own right. However, actually increasing intelligence, assuming we understand the whole context of such an alteration, would likely benefit humankind.*
> *British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

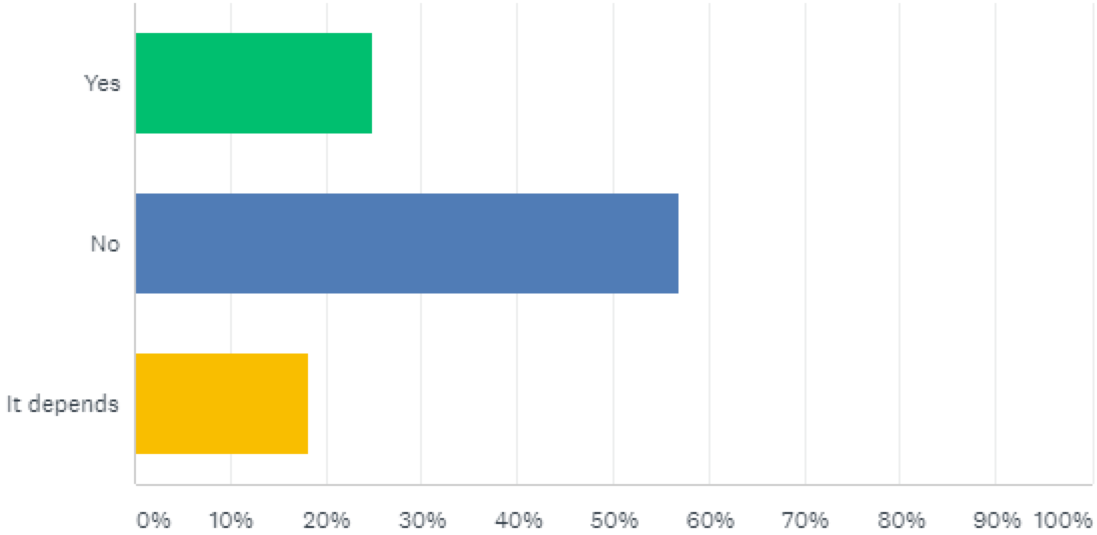
Diversity

Issues relating to gene pool diversity were raised and it was suggested that limiting use of the procedure could solve this problem.

> *Again, although this is objectively beneficial to the child, there is a risk that it would compromise genetic diversity if it became too widespread. As such, if scientists judge such a risk to obtain, such treatments should be fairly rationed to prevent said outcome. If the trait has a downside for the child, too, restriction may be wise.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Question 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
72 of 290 responded (25%)

No
165 of 290 (57%)

It depends
53 of 290 responded (18%)

Respondents who answered ‘Yes’

Health benefits

Some respondents expressed the view that the kind of modification described would confer health benefits on a future child which meant it would be acceptable to make.

> *Survival by being drought-resistant is clearly therapeutic for a child, and isn't the same as other 'super-human' traits like strength or speed.*
> *American female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *If it’s important to remain in health threatening drought areas, then yes, whatever enables them to carry on with vital important work safely should not be denied them.*
> *British male non-parent, 65+, secondary school educated, no genetic condition in family, not genetically tested*

> *It maximises the chance of the child to have a healthy life*
> *British female parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

One respondent suggested that though they supported access to this procedure the described scenario was approaching the limit of what they would find to be acceptable.

> *I am drawing the line here: though this has many of the same problems as the intelligence trait, conferring drought resistance in a drought-ridden environment is fundamentally a medically indicated procedure, and as such should be available; same as for diseases (Q11).*
> *German male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Benefits to the human species

Some respondents said that this kind of change would provide advantages to humanity as a whole and that meant it was acceptable to use it.

> *Changes to the genome such as this will contribute not only to their child's chances of survival but also that of the human race, by contributing a very useful characteristic to the gene pool.*
> *British male non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested*

It was suggested by some respondents that such changes might be necessary for the survival of the species.

> *Again, this is the sort of thing humanity needs to take us into the future. Reducing reliance on blind chance, and taking control of our genetics is a logical next step in our evolution.*
> *British male parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

> *This is sci-fi territory now. I strongly believe that in 2-3 hundred years from now we might have to "improve" our species in order to survive on this or another planet.*
> *Greek male parent, 35-44, postgraduate, no genetic condition in family, genetically tested*

It would resemble evolution

On a similar note, some respondents likened the effects of the procedure to those of evolutionary processes, which they suggested implied that it would be permissible to use it.

> *This is kind of like evolution, so maybe we should be allowed to do this. And this is a case of a real danger. Although it would not be fair to the people who cannot afford this. In the end if the human race is meant to survive, this will happen naturally through evolution.*
> *Dutch female parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *This sort of trait might easily evolve naturally - why not introduce it in a way which minimises suffering i.e. all those who can't tolerate drought die so only those that can survive to breed?*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

Privacy

One respondent said that the decision was a private one and Eli and Franc should therefore be able to take it themselves without the interference of others

> *The couple's decision is private. As a couple is responsible for a decision to have children, a decision to give children advantageous genes surely falls within the same scope of control.*
> *American male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

Similarity with other kinds of intervention

One respondent said that making this kind of modification was on a spectrum of related scientific interventions in the world designed to benefit human beings.

> *We've already done quite a lot of engineering of our world to satisfy our needs, I don't see why we shouldn't engineer ourselves.*
> *American female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

Respondents who answered 'No'

Safety and uncertainty of long-term effects

A number of respondents raised worries about safety and risks of use of the procedure.

> *There doesn't seem to be a way to properly test the risks of this.*
> *British female non-parent, 25-34, postgraduate no genetic condition in family, genetically tested*

> [xxx]…*Restrictions should apply for that long-term circumstances. No convincing prediction in this case.*
> *British female non-parent, 25-34, postgraduate no genetic condition in family, genetically tested*

Concerns about the possibility of causing unanticipated or off-target effects were raised.

> *Unless we suddenly become completely knowledgeable about everything that we are doing with the genome. And then fine!*
> British female non-parent, 25-34, graduate genetic condition in family, not genetically tested

> *Precautionary principle. It is extremely unlikely that one could alter this trait without altering a huge number of other physiological traits in unforeseen ways.*
> American male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

Availability of alternative options

A number of respondents expressed the view that tackling climate change itself, rather than adapting human beings so that they were better able to tolerate its adverse effects, would be a preferable approach

> *We're not saying that humans are perfect but we're pretty well adapted to most things. Perhaps the climate change one is a bad example but it's an issue that we could meet by changing our behaviours rather than changing ourselves.*
> British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

> *Again, fix social problems (pollution, dependence on fossil fuels, neoliberal economics, excessive individualism, competition) not people. Otherwise we don't deserve to survive.*
> British male non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested

> *We have a responsibility collectively to make a world that is fit for future generations and our resources would be better directed to taking action to allocate environmental degradation.*
> British female parent, 55-64, postgraduate, genetic condition in family, genetically tested

No health benefits

Some respondents said that since the alteration would not prevent disease of alleviate suffering it would offer no health benefit and so should not be allowed.

> *A gene associated with traits rather than a clear cut genetic disease should not be altered.*
> Singaporean male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

> *Using genomics for this sort of thing seems almost grotesque for me. I feel the science of genome editing should be used where possible to minimise suffering. This falls way outside of those parameters.*
> British male non-parent, 25-34, graduate, genetic condition in family, not genetically tested

> *There is no medical need here at all. It equates to creating a 'superior race' and is disturbing.*
> British female non-parent, 55-64, postgraduate, no genetic condition in family, not genetically tested

Children modified this way would not be human

Some respondents said that these changes would a new non-human or post-human species.

> *Such children would not be human beings, they would be a new type of human-like organism.*

> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *What would they be producing, some creature that was no longer fully human.*
> *British female parent, 55-64, postgraduate, genetic condition in family, genetically tested*

One respondent added that to make such changes would be eugenic.

> *This is the eugenic route to producing a super-race of humans*
> *British male parent, 65+, postgraduate, no genetic condition in family, genetically tested*

Concerns about what is natural

Some respondents expressed worries about disruption of natural processes.

> *This goes against survival of the fittest and is not natural.*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *Tampering with nature*
> *Pakistani female parent, 35-44, postgraduate, no genetic condition in family, genetically tested*

> *Eugenics and trying to disturb natural selection.*
> *British male non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

> *We don't know whether this will be used wisely by nature.*
> *Greek female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Unrealistic scenario

A number of respondents challenged the premise of the questioning, claiming that the scenario described was not realistic, given the complexity of the genetic bases of drought tolerance.

> *Once again, this is a highly misleading question for those with minimal understanding of genetics. Drought tolerance in plants is conveyed by a suite of genes and there is no reason to assume that in humans, ability to tolerate long periods without water, could be engineered.*
> *American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

> *This survey is now getting ridiculous.*
> *Singaporean female non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

> *This is just getting silly.*
> *Australian female parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

One respondent suggested that posing questions about more remote possibilities would influence how respondents answered earlier questions about less remote possibilities.

> *This is an absurd question and you know it. Including it is a strategic move by the Nuffield staff to generate a strong "no" response, thus indirectly helping legitimate the "yes" responses to the situations described in previous questions.*

> American male parent, 65+, postgraduate, genetic condition in family, not genetically tested

Consent

It was said that it would be wrong to use the procedure partly because the future person could not consent to it.

> *It would be morally and ethically wrong. because: i) Humankind has the intelligence and resources, to adapt the environment. ii) It would be an unnecessary genetic change, imposed on a culture, pre-birth, without the right or opportunity for the potential child to decline that intervention.*
> *Demographic data not provided*

Respondents who answered ‘It depends’

The urgency of the threat

Some respondents said that whether or not the procedure should be used depended on how immediate the threat was.

> *If the threat for child survival is imminent, then yes, such a procedure should be allowed, but if they are just anticipating that potentially in the future it may be of use then no.*
> *Spanish male non-parent, 18-24, postgraduate, genetic condition in family, not genetically tested*

Some respondents suggested that only if the human species as a whole were under threat would it be acceptable to use it.

> *Only in exceptional and urgent scenarios, e.g. if the human race were imminently at risk of extinction.*
> *British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *How likely is this trait to aid in the survival against climate change; is lack of water an immediate threat?*
> *British female non-parent, 25-34, postgraduate, genetic condition in family, genetically tested*

> *This would give the children a major artificial selective advantage for when climate change happens and the whole world is messed up, which isn't fair, but if we were in an apocalyptic society and it was the only way for the human race to survive then fair enough.*
> *Dutch female non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Availability of alternative options

Some respondents said that addressing climate change itself, would be preferable to using the procedure to alter people

> *I think all non-genetic methods should be tried first.*
> *British male non-parent, 25-34, college educated, no genetic condition in family, not genetically tested*

> *A better response would be to limit the population.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

One respondent who expressed this added that if there were no way of successfully countering climate change, it could be acceptable to use the procedure in those circumstances.

> *While this seems very useful, it seems like the wrong response to the problem in that rather than adapting to the impacts climate change, it would be better to try and deal with climate change itself. However, if that solution is not applicable to the situation, I can see the benefit of making humans that are better adapted to their surroundings.*
> *British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

The procedure resembles evolutionary processes

Some respondents compared this kind of change to those brought about by evolutionary processes and suggested that if the need were great enough it would be acceptable to use the procedure.

> *This happens over time anyway, it is called evolution. Again, one would have to tread very carefully however, if the alternative is massive loss of life and we risk that the rich may be able to get access to these advantages (which if the technology exists they would eventually) and the poor are left to die, we have to act rather than pretend is isn't happening.*
> *British male parent, 45-54, postgraduate, genetic condition in family, not genetically tested*

> *We have natural variations in our genetic makeup as adaptations to our indigenous environments, but evolution is not happening fast enough to keep up with climate change. As part of cohort studies, such 'experiments' could inform important research to address such problems. Inclusion must be determined randomly.*
> *American male non-parent, 35-44, graduate, genetic condition in family, not genetically tested*

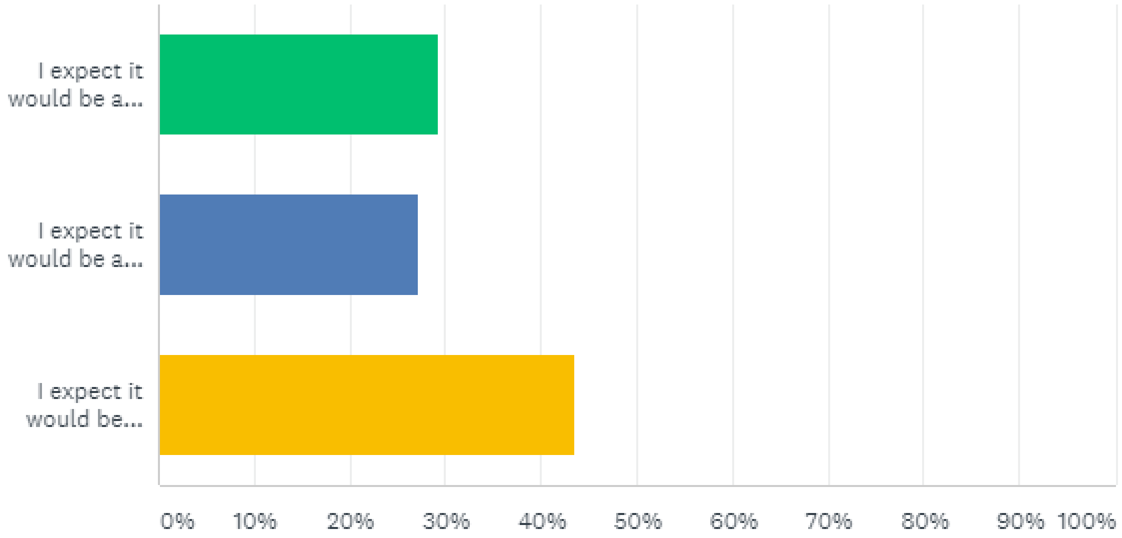
If it was accessible to all

It was also said that it would be acceptable to use the treatment only if everyone were able to access it.

> *I think I would only be open to this treatment if it was available to everyone and the allele was very well studied and was shown to not have negative side-effects.*
> *British female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Question 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
85 of 290 respondents (29%)

I expect it would be a worse place to live
79 of 290 respondents (27%)

I expect it would be different, but not necessarily better or worse
126 of 290 respondents (43%)

Respondents who answered ‘I expect it would be a better place to live’

There would be less disease and/or disability

A number of respondents said that they thought there would be less genetic disease and/or disability in a world in which genetic interventions were widely available.

> *Less disease and severe disability would be a good thing I think.*
> *Scottish female non-parent, 18-24, graduate, no genetic condition in family, not genetically tested*

> *Decreased mortality/better quality of life due to removal of genetic diseases is good.*
> *No demographic data provided*

In addition to likely increases in the quality of life for those that would otherwise have had genetic disease, some respondents said that people that would otherwise have been infertile, parents of children with genetic conditions, and the wider public might also benefit, though it was added by one respondent that the effects of the availability of such interventions would need to be monitored.

> *In terms of combating certain severe genetic diseases I feel that this would make it a better place to live, improved health of individuals with a better quality of life, and less strain on parents of those diagnosed with such a condition. It would also reduce the cost of healthcare when these serious conditions requiring a lot of expensive treatment and medical attention/equipment could be reduced.*
> *British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *Some of the heartache caused by infertility, child illnesses and disease would be lessened. However, there would need to be careful monitoring of this and perhaps restrictions on population growth, perhaps restricting numbers of children.*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

Genome editing should not be used for non-medical purposes

Some respondents said that genetic interventions should not be used to alter traits for reasons that do not relate to medical or health needs.

> *I do not agree with any selective traits that are not to combat disease or aid quality of life for these individuals.*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *I think the changes have to be to make healthier, more able bodied people, not just smarter, more cultured people. Health first.*
> *British female non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

One respondent explained that this was due to their views about the importance of genetic diversity.

> ***…** I do not agree with any selective traits that are not to combat disease or aid quality of life for these individuals. Humans still require genetic diversity and I worry that this kind of behaviour would have serious implications to this.*
> *British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

Another respondent defended the use of genetic interventions for health related reasons alone also suggested that non health, or ‘enhancement’ interventions might become acceptable at a certain point after it had been demonstrated that such interventions were safe

> *On balance, I remain a technological optimist - however, I think there should be a moratorium on any form of "enhancement" until we have safely and widely applied editing/modification technologies for disease treatment/prevention for at least a generation.*
> *British male parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

Need for legal limits and monitoring

Some respondents suggested that a world in which genetic interventions were widely available would be acceptable if certain other arrangements had been made, such as an appropriate legal framework and monitoring of outcomes.

> *I am assuming legal protections exist re protection from discrimination and ensuring the fair treatment of minorities. Overall I believe humans strive for a better world with more fulfilling lives and less suffering.*
> *British male non-parent, 55-64, graduate, no genetic condition in family, not genetically tested*

> *….there would need to be careful monitoring of this and perhaps restrictions on population growth, perhaps restricting numbers of children.*
> *British female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

> *As long as limits and controls are in place. We have been taking control over our own biology for centuries, mainly for the better, and gene editing is just the latest technology to help.*
> *British female parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

Concerns about societal impacts

Some respondents said that there were significant risks of societal inequalities being exacerbated by the availability of genetic interventions, though they said they believed that the benefits would outweigh the harms, eventually.

> *The large-scale consequences of widening social differences due to engineered genetic makeup cannot be ignored. Nevertheless, I am optimistic that — at least in the long term — the population-level advantages of improved human ability will outweigh the disadvantages. The same has already been seen with general improvements in health care: people with access to better care will always be better off. It is therefore an ethical imperative to make such possibilities available as widely as (and in the least biased manner) possible.*
> *German male non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

> *A world without genetic (and infectious) disease would be a welcome one. The danger is genetics promoting inequality between the rich and the poor, and the potential for it to create new social classes. This is not desirable...*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Responsibilities to make genetic interventions

One respondent said that it would be wrong to prevent access to genome editing because of the implications such technologies had to alleviate suffering.

> *Deciding not to go forward with possible genetic improvements would be akin to choosing not to produce tools or medicines. If we have the ability to reduce*

> *suffering and we should take it. A bias towards the status quo is unhelpful, and can cause needless pain.*
> American male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested

Cautionary points

A range of individual points and questions were raised by respondents which, though broadly supportive of the genetic interventions, were not all positive in tone. One respondent for example said that though they were optimistic about widespread availability of genetic interventions overall it was nevertheless very hard to imagine what such a world would be like.

> *I think the consequences would be impossible to predict in many ways. Would it lead to speciation of humanity into multiple, reproductively incompatible lineages? Would it lead to some sort of genomic meltdown due to epistatic interactions between different "improvements"? Would we do idiotic things to our children in the name of fashion? Who knows? All I can really say for sure is that it seems like it would be empowering people to more fully realize their hopes and dreams, and all else being equal, that's a good thing.*
> American male non-parent, 45-54, postgraduate, genetic condition in family, not genetically tested

Concerns were also raised about the diversity of the gene pool being compromised in a world where genetic interventions were easily accessible.

> *Humans still require genetic diversity and I worry that this kind of behaviour would have serious implications to this.*
> British female non-parent, 25-34, graduate, genetic condition in family, not genetically tested

One respondent suggested that the question simplified the issues and was hard to answer for that reason

> *Collating the three examples into one better/worse statement is very difficult as two seem much more "worthy" than the last example. On the whole, the ability to prevent disease and improve the life of children and parents would make the world a better place to live (depending on safety and regulation etc). Allowing people to select advantageous traits in children (musical ability/intelligence) will make our society a worse place to live - but there is a wide gulf between the two.*
> British female non-parent, 18-24, graduate, no genetic condition in family, not genetically tested

Respondents who answered ‘I expect it would be a worse place to live’

Access and social justice issues

Concerns about the societal impacts, including those on fairness and social justice, on a world in which genetic interventions were widely available was raised. Some respondents said that there was a risk that inequalities would be increased

> *Such a society would likely reinscribe current forms of bias and thereby heighten social inequities.*
> American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested

> *Will be place of inequality. Another reason for a competition, war etc.*
> Polish female parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

> *Given that broadly speaking we have not done well with wealth distribution a society with greater genetic interventions would only enhance the divides we currently have.*
> *British male parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Some were worried specifically about the potential for sharp divisions to emerge in society that would give rise to distinct classes, or even different species, of human being.

> *Development and use of heritable human gene editing would mark the advent of a new techno-eugenics that would inevitably give rise to human genetic castes and eventually to human sub-species.*
> *American male parent, 65+, postgraduate, genetic condition in family, not genetically tested*

> *As with animal breeding, given the tendencies of humans to favour particular interests, human breeding is likely to lead to creation of genetic class divisions, worse than a caste structure of society, which would eventually have its international dimension and thereby alter the world order.*
> *American male parent, 55-64, postgraduate, no genetic condition in family, not genetically tested*

Human beings would be likely to misuse the technology

Some respondents issued warnings about possible misuses of genome editing and expressed pessimism about the prospects that it is misused.

> *I don't trust humanity. Look who we put in office for president of the US. Maybe one day when we are bit more sophisticated as a species, have dealt with our race, gender, religion, ethnicity and class issues we would be able to revisit this conversation. But not now. I think terrible things would happen...terrible terrible things.*
> *American female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *Margaret Atwood, Octavia Butler, and several other writers can provide insight to worlds that seem to creepily similar to our own, now that we have powerful tools that we abuse! Let's not go down these roads*
> *Filipino female non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*

One respondent suggested that human beings should first aim to establish a ‘socially’ healthy society before using genome editing.

> *Given humans' track record of destructiveness and lack of consideration of not only other species but of other humans, I think our species needs to prove itself socially before it starts manipulating itself genetically.*
> *Canadian male non-parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

Safety and uncertainty of long-term effects

Again, respondents expressed scepticism that it would be possible to determine confidently that using genome editing in this way would be safe in the long term.

> *We would have no idea of the long term effects on the offspring and future generations.*
> *Australian male parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *We don't yet have a clue about the long term consequences. Social political processes are not genetically conserved. The proposal is an unstable evolutionary strategy.*
> *New Zealand male parent, 65+, postgraduate, genetic condition in family, genetically tested*

> ***….****The unknown unknowns of how epigenetics, environments, and myriads of unpredictable factors outside of labs interact in unexpected ways. We are nowhere near understanding life, but we have a strong desire to control everything.*
> *Canadian male non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Religious considerations

Some respondents cited the role religious belief might play in respondents' views about such a world; one respondent said that humanity is a gift that should be appreciated and not altered.

> *I am a religious person and draw a great deal from what I have learned in that tradition. We are created humans and our humanity is a gift. By altering that gift according to what we deem appropriate, we fail to be human. I try to stay away from quick comparisons to Nazism, but there is little difference between perfecting the Germanic race and perfecting "X" child. Both fail to recognize the value of a human life, even it be short and full of suffering.*
> *American male non-parent, 25-34, graduate, genetic condition in family, ng*

One respondent expressed the view that humanist models of value were inadequate to identify the ethical issues raised by genetic intervention.

> *The ability to alter genetics will not improve society. Firstly, the problem with society is the displacement of God and his replacement with non-absolutes leading to time+chance+energy humanism which is a useless standard for society. It offers only relativism and chaos which is bad for society. Secondly, man will continue to raise himself higher onto a pedestal and his pride will lead to the exploitation of genetic manipulation for evil - and it will not be identified as evil because of the prevalent attitudes of humanistic relativism….*
> *British male non-parent, 18-24, graduate, genetic condition in family, not genetically tested*

The nature of reproduction and parenting

A number of respondents suggested that character of reproduction, birth and parenting could change in a world where genetic intervention of the kind described was easily accessed.

> *It wouldn't necessarily FEEL like a worse place to live. However, it would involve a change in our posture towards children that would have potentially exceedingly far-reaching consequences, especially given the implicit transhumanism in a number of progressive ideological values (children as choices, same-sex couples as interchangeable with male-female couples, natural child-bearing as an obstacle to the desideratum of gender neutrality, etc., etc.). It would implicitly shift the begetter-begotten relationship of equality of nature to one in which the parent(s) and those performing the procedures functioned as the law of the child's existence, shifting in the direction of a creator-creation relationship. It would compromise the natural humanizing bonds that arise from natural child-bearing, and would probably have the effect of inviting the state to intervene between parent and child.*
> *British male non-parent, 35-44, graduate, genetic condition in family, not genetically tested*

Notions of medicalisation, commodification and 'designer babies' were all raised in this context.

> *This produces too many choices to couples, medicalises conception/pregnancy/parenting and sets too high expectations*
> *British female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *These 'designer babies ' would come at a cost and so it would become an elitist practice*
> *Australian female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *…the disappearance of the notion of children as 'gift' and the commodification of children; the inevitable rise in termination of unborn children found to be 'less than perfect'*
> *British male parent, 65+, postgraduate, no genetic condition in family, not genetically tested*

It would be better to improve society in other ways

It was said that changing certain features of society, such as societal attitudes towards diversity and the availability of support for those that need it, would be a better way of dealing with the issues at which genetic interventions were aimed.

> *Instead of fucking with the genome, let's improve societal tolerance and appreciation of difference. Let's improve government support and resources for individuals who live with difference. Instead of making value judgments about characteristics, and encouraging human beings to strive for control that may never manifest because of how complicated genetics/environment interaction will always be, let's learn to accept our quirks/shortcomings/differences, and put resources toward healing the actually sick.*
> *American male parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

Respondents who answered ‘I expect it would different but not necessarily better or worse’

Benefits of tackling disease

Some respondents said that a world in which genetic editing was widely used would contain a mixture of good and bad, with some comments to the effect that the availability of genomic interventions to treat disease would be welcome but unregulated or broader uses might create issues

> *In favour of gene editing for disease treatment, though would be concerned about regulation.*
> *Welsh female non-parent, 25-34, postgraduate, genetic condition in family, not genetically tested*

> *If diseases were eradicated it would be better. If the personal whims and cultural preferences of parents were allowed to influence genetic interventions, then it would be a worse place.*
> *British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *Better in the sense that genetic diseases could be eradicated, worse with the possibility of a biological upper class*
> *Welsh female non-parent, 18-24, college educated, no genetic condition in family, genetically tested*

> *It would be good to avoid the debilitating serious conditions caused by mutated genes which pose a significant threat to quality of life and overall survival. I also*

> *think that where possible and to an extent couples should be able to receive assistance in conceiving.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, genetically tested*

Hard to predict

Some respondents said that the question was too difficult to answer because it was so difficult to envisage what such a world would really be like.

> *Not really an answerable question.*
> *British male parent, 65+, college educated, no genetic condition in family, not genetically tested*

> *Some problems will be solved, but as with any new tech or policy there may be problems we can't predict.*
> *British female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *It's hard to know- and this is part of the problem. Historically we are terrible at predicting actual outcomes.*
> *Australian female parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

One person that took this said also that they thought it likely that many complications would arise

> *It could well be either a much better or a far worse place to live. I expect a large number of complications would arise as a result. Also, there are too many unanswered questions for me to feel confident that it would definitely be beneficial.*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Access and social justice

Some respondents expressed concerns about the impact on equality of the availability of genetic interventions

> *It would depend on which scenarios were allowed, how accessible they were and whether it would be abused to further inequality.*
> *British male non-parent, 18-24, college educated, no genetic condition in family, not genetically tested*

> *There would still be inequality due to other factors and it is inevitable that, at least in early stages, the better off would have better access to these procedures and benefit unfairly. I do believe positive changes could result from human genetic modification that would benefit the human race as a whole, though its impact could raise new social issues such as "natural" people with non-edited genomes being discriminated against, or vice versa.*
> *British male non-parent, 0-17, college educated, no genetic condition in family, not genetically tested*

> *In itself, such genetic interventions are in my opinion neutral; whether it was a better or worse place to live would depend on who controls the availability of such changes, the prior and resulting (class) structures of the society etc. In our current society, there are reasons to suspect it would be worse - but there is no necessity that that would be the case.*
> *German male non-parent, 35-44, postgraduate, genetic condition in family, not genetically tested*

Implications for diversity

Some respondents raised concerns about how diversity and disability might be viewed in a world in which genetic intervention was widely available

> *I believe we need to live with disease and disability. If there were less it could lead to a less tolerant society and take us back to the dark ages where only the healthy were considered worthy of living and the rest 'left on the wayside'. Not a pleasant thought and so we must tread carefully into the future and not allow the scientists to take over.*
> *British female parent, 55-64, college educated, genetic condition in family, not genetically tested*

> *Social justice concerns and the expression towards disability and tolerance. New way of tackling environmental problems rather than addressing the actual issues.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

These changes would be a par with other kinds of genetic intervention

It was said that such changes would be continuous with other ways humans have intervened in the world for many years

> *The principle seems disturbing and wrong. However, we have been doing this stuff to animals for 1000s of years and so we can do it in humans too. Only time will tell how positive vs negative it can turn out for humanity.*
> *British male parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

These changes to society are inevitable

One respondents said that such changes were inevitable and that they would come to be seen as normal.

> *Eventually, all these things will happen, and at some point it will be acceptable and part of 'normal' culture in many places. Going through the ethical process slowly allows for a period of adaptation in the way technology is perceived.*
> *British female parent, 35-44, postgraduate, no genetic condition in family, genetically tested*

Question 16

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

Of 320 respondents, 114 answered the final question asking if they had anything to add to their previous answers. A range of themes, some of which were present in answers to previous questions, could be identified in the answers to these questions.

Feedback on the survey

Some respondents used their final comments to comment on the scenarios described in the survey, with some claiming that it displayed a bias in favour of human reproductive applications of genome editing.

> *This survey on the whole is highly biased toward garnering responses that support any and all interventions in the germline. It is a poor tool for assessing public views.*
> *American female non-parent, 55-64, postgraduate, genetic condition in family, not genetically tested*

Particularly, some respondents suggested that description of the impacts on individuals making use of genome editing and their future children was unduly emphasised and there was inadequate attention paid to potential wider societal effects.

> *[…]The scenarios featured in the survey involve individuals/couples desiring a healthy child, where the technology is deemed safe (and no viable alternatives are presented). The casting of the issue in this way predisposes respondents to think of themselves as heartless if they oppose IGM and, thus, the question(s) are set up to produce a highly skewed result, far afield from much larger social issues. Chief among these are: 1. The advent of a consumer-driven eugenics. This time around, eugenics would not be state-driven but would take an insidious form, proceeding privately and incrementally in fertility clinics and physician's offices. A tacit acceptance of eugenic aims would demean and impoverish us as people and as a society. 2. Treatment vs. Enhancement. The acceptance of IGM would not stop at treatment decisions and applications. The bright line between treatment and enhancement is illusory, as one person's treatment is another's enhancement, and medical practice is replete with examples of how something started as a treatment and slid into cosmetic or enhancement usage. Once permitted for the treatment of disease, not far behind will be the modification of the human germline for enhancement purposes. 3. Social inequity between the "haves" and "have nots." Especially serious here is that privilege and prejudice would be driven directly into biology, deep and beyond reach. No group of specialists is equipped or ethically justified in moving ahead with IGM. Given the potential impact on all of us, on the human species as a whole, a full and publicly inclusive discourse over an extended period is absolutely necessary. That "public" must include communities addressing reproductive justice, disability justice, and public health, as well as people in the arts, humanities, ethics, and religion. And that "public" – rather than being asked for a simple "yay" or "nay" – must understand what is being asked and what is at stake. We are far from this kind of public discourse.*
> *Demographic data not provided*

> *The survey gives almost no background information about why human germline modification is so consequential and controversial. Regarding safety, it says nothing about how germline editing could be "judged to be safe," who would make that call, and what human experimentation or follow-up evidence would be required. It doesn't*

> *question whether there is a need for this technology to prevent the transmission of serious inherited disease, given other options available (problematic as those may be) The survey is structured to focus attention on individual couples rather than on societal consequences. It makes no reference to public policy (including the legal prohibitions in effect in 40+ nations), nor to the likely dire impacts on social justice and equity*
> *Filipino female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*

> *[…]It is shocking that the Nuffield Council would publish such a badly done survey. E.g.: there is not a single issue that deals with any societal issues apart from eugenics; there is no mention of alternatives even within the framework of reproductive medicine. There is no reflection - anywhere - of the implicit ethics the survey applies. It is an eugenics-enabling survey - even if people would choose "no" on the respective answers.*
> *Demographic data not provided*

> *This survey is monstrously slanted.*
> *British/American male non-parent, 65+, postgraduate, not genetically tested*

One detailed response making these kinds of claim raised a wide range of concerns including allegedly unrealistic characterisations of the safety of the described procedures, no attention to issues such as consent, the value of an ‘open future’, the availability of alternative procedures, potential impacts on inequality and the existence of international legal prohibitions on the use of germline modifications.

> *The way in which this public survey is structured and framed is extremely disturbing and disappointing. It seems deliberately designed to produce results that can be claimed as showing “public support” for human germline editing for reproduction. Surely you cannot expect that anyone whose knowledge of the issue is based entirely or mostly on what’s provided in the survey would be able to respond in a meaningful way. The survey’s three scenarios focus respondents’ attention solely on the individual situations and desires of the hypothetical couples contemplating their personal reproductive decisions, with no historical or social context whatsoever. There is a completely unwarranted assumption of “safety,” when in reality judgments about what is considered “safe enough” are themselves subject to contestation and disagreement. There is no mention that in the vast majority of cases in which germline editing would be even considered – to prevent the transmission of serious inherited disease – it would be unnecessary (and medically contra-indicated) because of the availability of safer alternatives. There is similarly no acknowledgment of issues of consent – not just of the engineered children being contemplated, but for all future generations of their children as well. The importance of preserving children's "open future" is likewise missing. The survey’s failure to acknowledge the potentially dire societal dangers of permitting human germline modification is a very serious shortcoming. There is no consideration of the unlikelihood of actually being able to limit human germline modification to the medical-sounding reasons presented in most of the scenarios. What is far more likely is that permitting it for any reason would lead to a world in which affluent parents could purchase the latest genetic upgrades for their offspring, leading to exacerbation of already existing (and shameful) inequities and discrimination. It takes little imagination to foresee that this could usher in an era in which genetically enhanced “haves” are perceived to be superior to the genetically unenhanced “have-nots” – in other words, an era in which we would witness the emergence of a market-based, high-tech eugenics. Finally, there is no mention that dozens of nations around the world, including most with advanced biomedical / biotech sectors, have deliberated about this issue, and decided to legally prohibit human germline modification. The existence of a binding international treaty that prohibits human germline modification is likewise ignored. This survey is unworthy of the Nuffield Council and its efforts to maintain its international reputation as an independent body. I hope you will decide to discard it and start this aspect of your public consultation from scratch.*

> *Demographic data not provided*
> *Marcy Darnovsky, PhD, Executive Director, Center for Genetics and Society*

Others expressed more positive views about the survey or said that it was helpful or interesting

> *Thank you for undertaking this project, and seeking public feedback. Though I am a professional philosopher and bioethicist, I have confidence in laypersons to give thoughtful serious answers to a survey of this kind. Perhaps not all will, but many or even most will. That is critical. Indeed, were I my 22 year old self, before all of my professionalization, I would have been more than willing and interested in completing this survey.*
> *American female parent, 35-44, doctorate, genetic condition in family, not genetically tested*

> *This is a really, really cool survey.*
> *British male non-parent, 35-44, postgraduate, genetic condition in family, genetically tested*

> *Good stuff! Thanks :)*
> *German male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *Good to have the opportunity to voice this.. I hope it adds to a change in the trajectory of gmo progress.*
> *Australian female non-parent, 45-54, postgraduate, genetic condition in family, genetically tested*

There is nothing wrong with human reproductive genome editing, in principle

Some respondents chose to express their views that genome editing was not wrong in principle, pointing out that intervening in nature is characteristic of many areas of human activity including animal breeding and healthcare.

> *Many people disagree with genetic modification as they think it is "unnatural" or "playing God", however selective breeding is something humans have been doing artificially for millennia to edit the genome and nobody seems to take issue with that.*
> *British male non-parent, 0-17, secondary school educated, no genetic condition in family, not genetically tested*

> *This should all be obvious! Make people healthier and happier! Interfering with nature is what we do all the time, there's absolutely nothing morally wrong with it! Is not difficult!*
> *British male non-parent, 18-24, postgraduate, genetic condition in family, genetically tested*

One respondent suggested that concerns about genome editing were more appropriately directed towards other issues that might arise in the vicinity of genome editing such as commercial profit.

> *There is nothing intrinsically wrong with genetic intervention, so long as medical experts determine the purpose of such intervention rather than it being determined by profit or personal whims of parents.*
> *British male non-parent, 18-24, postgraduate, genetic condition in family, genetically tested*

Genome editing should not be used for non-medical purposes

Some respondents used their comments to express the view that genome editing should only be used in human reproduction for reasons relating to health.

> *I feel that allowing this treatment in the UK to prevent serious genetic disorders is the only moral option, however, legislation must be clear that it can not be used to introduce socially desirable traits and must only be used to improve the health of future generations.*
> *British male non-parent, 35-44, postgraduate, no genetic condition in family, not genetically tested*

> *Anything that benefits peoples health and lives should be encouraged. Anything that makes one person superior to another,-maybe not.*
> *British male non-parent, 65+, secondary school educated, no genetic condition in family, not genetically tested*

> It is a very complex situation and one which might lead to some demands that I am not comfortable with. As long as it is to prevent inherited illness, I am very happy with it.
> *British female parent, 55-64, postgraduate, genetic condition in family, genetically tested*

> In my opinion, the only excuse to interfere with genetics in this way would be for severe health benefit, where otherwise people would not have any quality of life, but this threshold should be high. As people cannot be trusted, I think that all other forms of genetic modification of humans should be outlawed.
> *British female non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

Beauty, strength and intelligence were some of the traits that respondents picked out specifically as ones that they thought should not be modified with genome editing procedures.

> *There were no questions on changing physical appearance through gene editing. I think procedures should only be used for medical purposes otherwise the pressure on people to be stereotypically 'good looking' would be too great.*
> *British female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

> *…. I would like to explicitly note that if there was a question about the introduction of non-human genes for "additional strength" or "increased intelligence" or "glowing skin" that my answer would be an extremely firm "no."*
> *British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

Wrongness of preventing access to human reproductive genome editing
Some expressed strong views that there were moral duties to use genome editing to prevent genetic conditions. It was suggested by some that opposing the use of such techniques to prevent genetic conditions was morally equivalent to causing them,

> *If there is anything which can prevent unnecessary suffering for infant or parents I believe if we are able to alleviate that it should be done.*
> *Demographic data not provided*

> *Bioethicists who argue against permitting children to be free of debilitating illnesses are equivalent to those who support child rape.*
> *American male non-parent, 18-24, postgraduate, no genetic condition in family, not genetically tested*

> *The potential gains from this line of biotech development are so incredible that I believe it would be worse than any historical war crime to prevent them being pursued.*
> *British male non-parent, 25-34, college educated, no genetic condition in family, not genetically tested*

One respondent elaborated on this point by observing that use of genome editing procedures in human reproduction is inevitable and that focusing on devising appropriate regulation would be the better response.

> *Having the power to reduce suffering / improve lives and not using it is utterly immoral. Once the tech exists, it will be used. Guaranteed. Those societies that choose to overregulate themselves or succumb to squeamishness will find themselves at a substantial disadvantage. It will happen. Better help it happen well.*

> British male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

Concerns about reactionary arguments

Some respondents made predictions about the likely nature and trajectory of public debate about heritable genome editing procedures in humans and warned about the prominence of arguments based on naturalness, designer babies or slippery slopes, and ‘public paranoia’.

> *I have a medical research background, but appreciate many will approach this from an uncertainty regarding the unfamiliar, and not always be comfortable with the opportunities genetics may provide. I imagine arguments citing what's natural will feature prominently, but hope to be pleasantly surprised!*
> Demographic data not provided

> *I request the scientific community bans the term 'designer baby'. Its is not scientific, it panders to the tabloids, misinforms the public, and is a barrier to progress.*
> British female non-parent, 55-64, graduate, genetic condition in family, genetically tested

> *Gene editing is a revolutionary technology that can play a role in addressing some of the world's most vexing problems. Public paranoia shouldn't hinder its progress.*
> American female parent, 45-54, graduate, no genetic condition in family, genetically tested

One respondent suggested that this kind of argument should not feature in policy formation.

> *There will be a lot of irrational fear of these kinds of intervention just because they are different to what has gone before. They should not be subject to restrictions or moratoriums just because of hypothetical or slippery-slope arguments. The policy should be that there is no policy except until demonstrable harm has been proven.*
> American male parent, 35-44, graduate, no genetic condition in family, genetically tested

Safety and uncertainty of long term consequences

Concerns about the uncertainty of the long-term effects and safety implications of using genome editing in human reproduction that featured in responses to many of the survey’s other questions were raised in response to this question

> *From current knowledge, it appears the genome editing technique in question - CRISPR - has lots of issues - while it may correct a gene, it may leave lots of unintended, off-target changes that cannot be easily scanned for. Perhaps it is best to do more research on human embryos first to really assess the technique before it is used in the clinic.*
> Singaporean male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested

> *How do you know what the long term affects would be with this experimentation?*
> Australian female parent, 35-44, college educated, genetic condition in family, not genetically tested

> *I would the wording about "considered to be safe, but there may be some risks, etc." to be rather too vague. To me, that is exactly where the dividing line is, since the rights being balanced are the rights of the parents to do what they wish with their own bodies, versus the rights of their child not to be disabled or deformed, not to be the subject of speculative medical experiments, etc.*
> American male non-parent, 45-54, doctorate, genetic condition in family, not genetically tested

> *Just a reminder that the safety of any given gene editing procedure will never be only a technical calculation by scientists and clinicians but a judgement about what threshold of risk is acceptable and ultimately about what counts as a risk and what is deemed not worth*

> *considering. gene editing will be more socially robust if these judgements are made by a wider group of participants, including patients, rather than by closed expert committees.*
> *British male non-parent, 35-44, doctorate, genetic condition in family, not genetically tested*

Need for public engagement

The importance of public debate and gauging public opinion on the ethics of heritable human genome editing was also raised in response to this question.

> *The most important thing is a wide and intense discussion about this topics which should be based on knowledge and scientific proved information.*
> *German male non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*
>
> *This is a complex matter and quite difficult to decide through multi-choice questions. It is something that needs to be made a matter of extensive public debate and consultation and should only be permitted by specific legislation. It should not be permitted on an unregulated ad hoc basis.*
> *Female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*
>
> *Specific attention should be paid to the moral charge of technologies, with anticipatory and empirical studies, as well as public opinion surveys (as this one). Focusing on calculating risks and benefits alone will be insufficient.*
> *Female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

One respondent highlighted the need for wide participation in public discussion of these topics.

> *Let as many people from different backgrounds as possible reply here. Use the information to let regulatory authorities and parliament know the need of most people and the concerns of the rest and protect all of us.*
> *Greek Female non-parent, 25-34, postgraduate, no genetic condition in family, not genetically tested*

One respondent, who also criticised the Nuffield Council survey for many of the reasons described above, said that surveys can sometimes undermine public debate by serving as an inadequate proxy for meaningful public consultation and engagement.

> *The online survey format also raises serious questions. In their book "Genetic Politics: From Eugenics to Genome," Tom Shakespeare and Anne Kerr note that surveys too often replace serious debate--and function to sideline dissent: "pressure groups that are knowledgeable and critical are often marginalized in favor of the so-called general public, whose opinions are accessed through a range of surveys and opinion polls. . .Survey results can thus become a substitute for proper public debate, by ignoring or 'exoticizing' special interest groups." I would go further: to the extent that many in the "general public" may not be familiar with the issues involved in human gene editing, the survey--meant to gather information--may actually function as persuasion, much as "push polling" does in the U.S. Respondents may come away with the belief that human gene editing is a safe way to obtain a healthy child. That the survey is online is also problematic, because it means that the people with the greatest reason to be concerned about these new advances--people with disabilities--are less likely to be able to access the survey. The inconsistent availability of accessible Internet, and the segregation and poverty of people with disabilities, mean that key responses are likely to be lacking, compounding the existing bias of the survey itself--in which couples contemplating future children have names and pictures, while disability exists as an abstract future to avoid. In their 2015 article "CRISPR Democracy: Gene Editing and the Need for Inclusive Deliberation," Sheila Jasanoff, J. Benjamin Hurlbut, and Krishanu Saha write that "[t]he challenge for democracy and governance is to confront the unscripted future presented by technological advances and to guide it in ways that synchronize with democratically*

> *articulated visions of the good." If that ideal is to be achieved, then a broader, deeper, and more balanced approach to public input will need to be adopted.*
> *American male non-parent, 45-54, postgraduate, no genetic condition in family, not genetically tested*

Personal and reproductive freedom

Some used their comments to express the view that individuals should be entitled to make their own decisions about using human reproductive genome editing

> *Ultimately I believe that everyone has the rights to make decisions of this sort unless they result in harm to the individual, those affected or society in general. I addition I also believe that if it is technically possible it will happens….*
> *Scottish male non-parent, 55-64, postgraduate, genetic condition in family, genetically tested*
>
> *Governments should not interfere so much with the free and considered choice of individuals regarding those individual lives. They should neither mandate humans be crippled, nor should they mandate the creation of Supermen.*
> *American female non-parent, 25-34, graduate, genetic condition in family, not genetically tested*
>
> Freedom is good; government is bad.
> *Demographic data not provided*

Predictions about future use of human reproductive genome editing

Some respondents used their comments to make predictions about how genome editing would be used in the future.

> *Very interesting survey, makes one think. One day there will be designer humans made to explore space, wage war, and inhabit new environments, such as the oceans. Wish I could be there to see it. But it would mean much more control...*
> *American female parent, 65+, graduate, no genetic condition in family, not genetically tested*
>
> *Somatic cell gene editing is likely to become the norm withing 10 years (for example for certain blood diseases such as sickle cell anemia. Eugenics, involving cell line gene editing (e. g. musical ability) must be avoided, though it may proceed illegally in very rich people outside of the law.*
> *British male parent, 65+, postgraduate, no genetic condition in family, genetically tested*
>
> *I think that genome editing is an inevitable part of humanity's future. If policy makers accept this and look at the wider social implications then this could be a positive move.*
> *British female parent, 55-64 postgraduate, no genetic condition in family, not genetically tested*

Relevance of guidance

One respondent cited the relevance of the European Council’s Principles of Responsible Innovations

> *I hadn't expected our Principles for Responsible Innovation to be as relevant. But I like them in this context: 1 Social purpose is clear - I felt that I could endorse the use of genetic tech where a clear social purpose involving the ending of suffering is possible. But where suffering is not involved and the purpose if social engineering, I don't think it is relevant. 2 Anticipates broader impacts - I am not sure if this is still a caveat (although, as with all complex procedures, there are some risks and there can be no guarantee of success) then this treatment is advisable. In germline editing the unintended consquences could be profound and we would need really hard clear evidence that the treatment does what it says it will do and nothing else. Also the other impacts you mentioned on availability, targeting etc are also important. 3 Radical transparency - is about how do we know it will do what it says, who*

> *governs it and how have they come to the conclusions on efficacy, purpose, slippery slope, legal implications etc etc that they have. without this I don't think we can be confident that this technology is being used wisely and without unintended consequences or opening the door to less desirable treatments. Stakeholder involvement - patient groups and those suffering from these diseases should be heavily involved in helping assess these diseases too and their views and concerns a significant part of the decision making process. society should also be part of this debate as you are trying to do. Have you send this specifically, in person, to the NGOs involved in the synbio moratorium. I hope so, I hope that you would send individual emails to them asking for their considered views. I think the academic community has far too much sway over this, simply because others don't feel confident in their judgement or are not asked and real steps taken to involve them.*
> *British female parent, 55-64 postgraduate, no genetic condition in family, not genetically tested*

Commercial drivers

One respondent said that commercial factors would be important in how applications of human reproductive genome editing were developed.

> *The profit motive is the strongest driver of the use of CRISPR, TALENS, etc. not a concern for human wellbeing.The precautionary principle urgently needs to be applied and a global framework for states to do so needs to be negotiated. This should involve everyone, not just proactionary scientists who stand to profit from the use of these technologies.*
> *Canadian male non-parent, 25-34, graduate, no genetic condition in family, not genetically tested*