

Bioethics in the classroom

Karen Stephens

◦ Bioethics in the classroom

Genome sequencing

Genetic engineering

Gene editing

Resources

Genome sequencing

Direct to consumer genetic testing

Flipped learning: Prior reading of selected articles

DNA-screening test 23andMe launches in UK after US ban

From <http://www.theguardian.com/technology/2014/dec/02/google-genetic-testing-23andme-uk-launch>

Article by Samuel Gibbs on Tuesday 2nd December 2104

The Google-backed genotyping service can screen for common genetic diseases such as cystic fibrosis or sickle cell anaemia



A kit from 23andMe. The service allows members of the public to have their DNA analysed. Photograph: 23andMe

Genetic testing company 23andMe is launching its personal genome service in the UK after it was banned in the US.

The service allows people to send their saliva in a testing kit to have their DNA screened for genes associated with certain inherited conditions, such as cystic fibrosis or sickle cell anaemia, and other genetic markers relating to parts of their lives and ancestry.

"We can take complicated genetic information and distill it in language that people can actually understand," the 23andMe chief executive Anne Wojcicki said.

"The genome is fascinating, and it's the most exciting scientific revolution of our lifetime. The goal is to keep people engaged with their own genome, so that they know what it means for them and then keep them abreast of the scientific discoveries as they unfold."

The spit kits cost £125 and are sent to the Netherlands before testing in the US. The results, which take approximately six to eight weeks, allow users to both browse the raw code of their genome and use tools to investigate their genetic makeup.

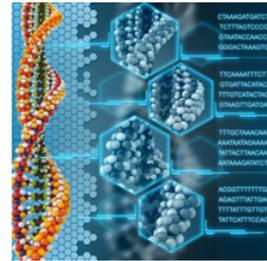
'DNA isn't something scary or all about disease'

The data is used to generate reports explaining common genes and genetic differences, such as how people metabolise caffeine to why some respond better to exercise. It also produces ancestry reports and further information as new research is published but does not advise on health matters. People could take the data to a doctor, however.

The data is stored encrypted and separated from identifying details on 23andMe's servers, accessible only to the subject. People can share their anonymised genetic data with researchers as part of a 600,000-strong genetic database, with their doctor or family, or remove it from the servers entirely.

23andMe Is Terrifying, but Not for the Reasons the FDA Thinks

The genetic-testing company's real goal is to hoard your personal data
By Charles Seife | November 27, 2013



Tomorrow's Medicine

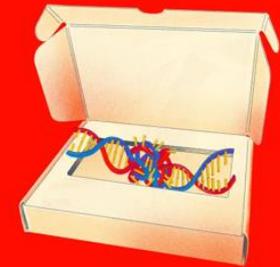
SA Forum is an invited essay from experts on topical issues in science and technology.

If there's a gene for hubris, the 23andMe crew has certainly got it. Last Friday the U.S. Food and Drug Administration (FDA) ordered the genetic-testing company immediately to stop selling its flagship product, its \$99 "Personal Genome Service" kit. In response, the company cooed that its "relationship with the FDA is extremely important to us" and continued hawkling its wares as if nothing had happened. Although the agency is right to sound a warning about 23andMe, it's doing so for the wrong reasons.

Since late 2007, 23andMe has been known for offering cut-rate genetic testing. Spit in a vial, send it in, and the company will look at thousands of regions in your DNA that are known to vary from human to human—and which are responsible for some of our traits. For example a site in your genome named rs4481887 can come in three varieties. If you happen to have what is known as the GG variant, there is a good probability that you are unable to smell asparagus in your urine; those blessed with the GA or AG varieties are much more likely to be repulsed by their own pee after having a few spears at Spargelfest.

At first, 23andMe seemed to angle its kit as a fun way to learn a little genetics using yourself as a test subject. ("Our goal is to connect you to the 23 paired volumes of your own genetic blueprint... bringing you personal insight into ancestry, genealogy, and inherited traits," read the company's website.) The FDA had little problem with the company telling you why you had dry ear wax (rs17822931) or whether you're likely to sneeze when you look at a bright light (rs10427255).

How DNA Testing Botched My Family's Heritage, and Probably Yours, Too



By
Kristen V. Brown
1/16/18 10:35AM

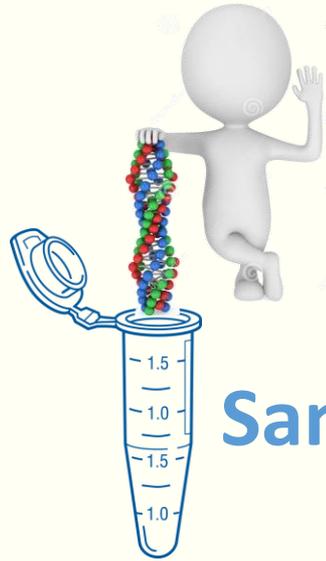
Taken from: <https://qizmodo.com/how-dna-testing-botched-my-family-heritage-and-probab-1820932637>

My grandfather was caramel-skinned with black eyes and thick, dark hair, and until he discovered that he was adopted, he had no reason to suspect that he was not the son of two poor Mexicans as he'd always been told. When he found his adoption papers, according to family lore, he pestered the nuns at the Dallas orphanage where he had lived as an infant for the name of his birth mother. Name in hand, at 10 years old, he hopped a bus to Pennsylvania, met his birth mother, and found out that he was actually Syrian.

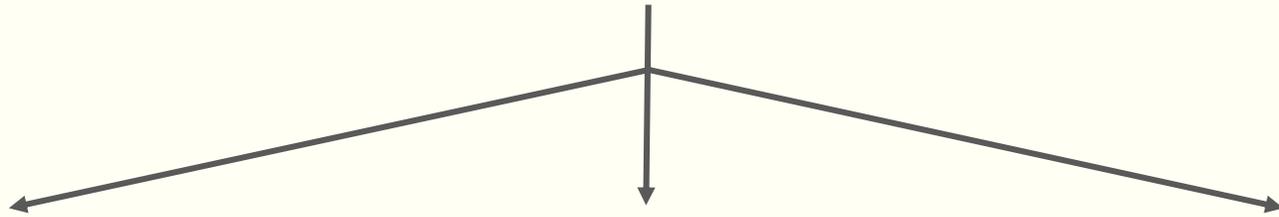
At least that's what we thought until my Aunt Cat mailed a tube of her spit in to AncestryDNA.

Genome sequencing

Direct to consumer genetic testing



Same DNA



AncestryDNA



23&me



National Geographic



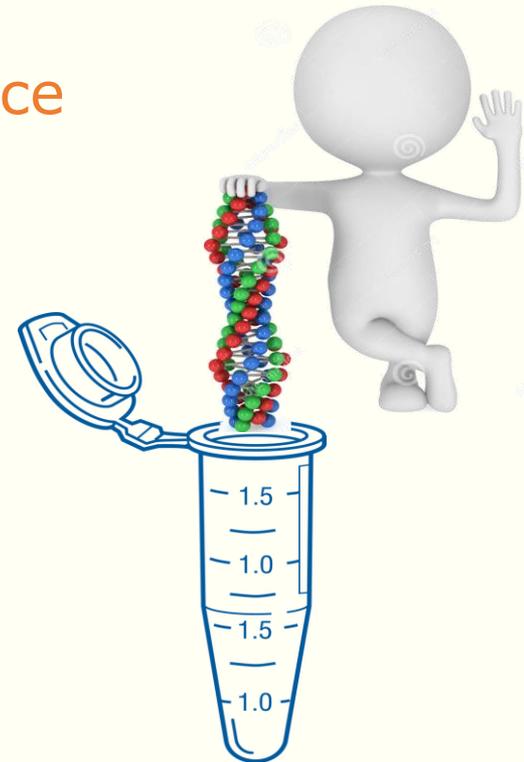
Genome sequencing

Direct to consumer genetic testing: the issues

Critical thinking:

Discussion to agree what issues may arise

- The **validity** of some claims about what DNA results mean has been questioned
- Results need to be declared for **insurance**
- Genetics is **probabilistic**
- Data **privacy**
- Inherently genetic data interpretation is **not absolute** because it compares to the DNA held in a database from people today



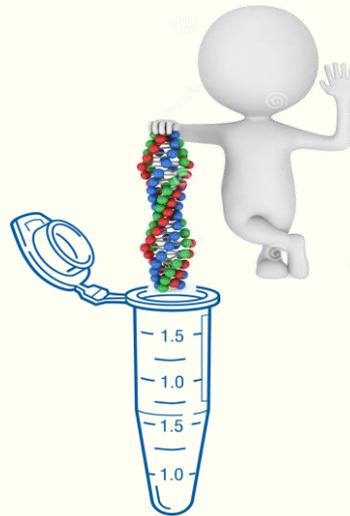
Genome sequencing

Direct to consumer genetic testing: the issues

Line of agreement:

What do you think and why?

Would you use direct to consumer genetic testing?



I would send off / my
DNA for testing

I would NOT send off
my DNA for testing

Agree

Disagree

10

1

Genome sequencing

Direct to consumer genetic testing: the unexpected

Narrative / life-changing:

Why these questions are relevant to everyone

Catching a killer: what if it's not alternative parentage or health risk but the presence of a murderer in the family revealed by your DNA?

- California 1976 – 1986
- 12 murders
- 50+ rapes
- 'Golden State Killer'



Genome sequencing

Direct to consumer genetic testing: the unexpected

'Golden State Killer'

1. Crime scene DNA retained
2. Matched to data from ancestry website
3. Discarded sample obtained from suspect family member



Golden State Killer suspect

◦ Bioethics in the classroom

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Genetic engineering

Acceptable uses of genetic engineering

Line of agreement:

What do you think and why?

Scientists should be allowed to use GM technology to...



... develop new disease-resistant varieties of wheat.

Agree

Disagree

Genetic engineering

Acceptable uses of genetic engineering

Line of agreement:

What do you think and why?

Scientists should be allowed to use GM technology to...



... develop new wheat varieties with higher yields

Agree

Disagree

Genetic engineering

Acceptable uses of genetic engineering

Structured discussion leading to scientific argumentation:
A. Providing context

Evaluate whether genetic engineering of crops can contribute to global food security.



Jenny is a young researcher in Developmental Studies. She is investigating **whether innovations in genetic engineering of crops can provide improvements in global food security**. Her area of research is new and has been funded because it relates to 2 big issues that are being debated globally:

- (1) Humankind's increasing understanding of genes, their influence on crop traits and ability to genetically engineer crops means that we have the **opportunity to change crop genetics at a faster rate** than previously possible. Opinions vary on whether we should do this.
- (2) The world population continues to grow, meaning that the growth, processing and transport of food to **ensure secure access to a varied diet for all people**, in a world experiencing global climate change, is increasingly challenging. Solutions to improve global food security are being actively sought.

Jenny's job is to consider the variety of opinions and evidence to come up with a conclusion on whether innovations in genetic engineering of crops can provide innovations in global food security.

Tasks:

1 – Read the story

2 – Think about the issue. Do you feel that we should use genetic engineering to help improve global food security?

Genetic engineering

Acceptable uses of genetic engineering

Structured discussion leading to scientific argumentation:

B. Providing structure

Evaluate whether genetic engineering of crops can contribute to global food security.



Bioethical framework

The bioethical framework for Food and Nutrition professionals requires them to consider:

1. Beneficence (*doing good*)
2. Nonmaleficence (*not doing harm*)
3. Justice (*treating others equally and fairly*)
4. Autonomy (*giving other people the options of choice*)

Genetic engineering

Acceptable uses of genetic engineering

Structured discussion leading to scientific argumentation:

B. Providing structure

Evaluate whether genetic engineering of crops can contribute to global food security.



Bioethical framework

The bioethical framework used at GCSE is simpler than this and requires you to consider:

1. Personal
2. Social
3. Economic
4. Environmental

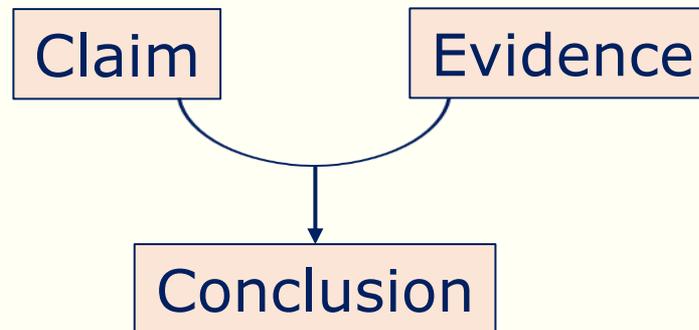
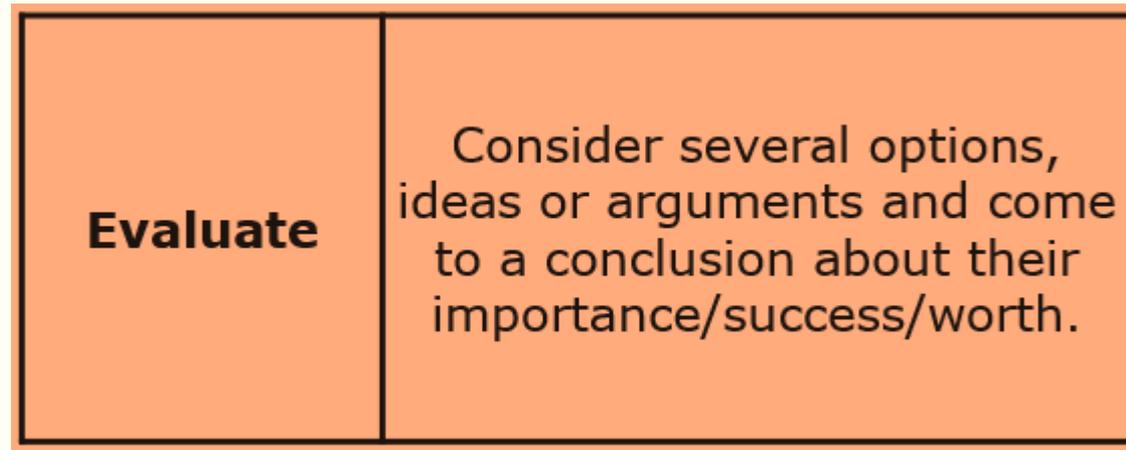
implications and to decide which are most important so you can draw a conclusion.

Genetic engineering

Acceptable uses of genetic engineering

Structured discussion leading to scientific argumentation:
B. Providing structure

The command word **evaluate** requires a combination of claims, evidence to support those claims and the ability to link the 2 in a conclusion



Genetic engineering

Acceptable uses of genetic engineering

Structured discussion leading to scientific argumentation:

B. Providing structure

Claim

'Scientists should be allowed to use genetic engineering to develop new plant varieties for agriculture, for example disease-resistant wheat varieties.'

Evidence

'Humans have been selecting traits in plants beneficial to agriculture (and plant health) through artificial selection over many generations without causing problems.'

Conclusion

'So altering wheat to become disease-resistant is a positive development as it mimics the process of artificial selection, but also speeds up the process of introducing positive traits into agriculturally important crops.'

Genetic engineering

Acceptable uses of genetic engineering

Structured discussion leading to scientific argumentation:
C. Evaluating claims

Evaluate whether genetic engineering of crops can contribute to global food security.



I work as a campaigner for the Soil Association. My last project was working with a group of people to support local purchasing. Now I am working on the traceability of organic foods through the food system.

My personal view is that we need to be eating more sustainably. To be able to do this, food should be produced ethically and people need to be educated about the impacts of their **personal food decisions**. I think that organic food is nutritional, ethical and good for the environment and I know that the Soil Association certification provides reassurance of their food. I find the interference make-up of crops abhorrent and I think the genetic engineering of any organisms, including those for consumption is fundamentally and



Andy

For	Against
Issue	Issue
Issue	Issue

I work for one of the world's leading agriculture companies. We provide genetically engineered seeds to improve crops in a variety of ways. For example:

- Biofortification improves the nutritional quality of food from crops, to combat nutritional imbalance and deficiencies
- Increased yield allowing farmers to gain greater economic benefit from farming the same area
- Resistance to common pests, often using a gene from a soil bacterium that produces insecticidal toxins
- Resistance to herbicides, so that farmers can spray their fields to remove weeds without affecting the crop growing there

For the most part our genetic solutions enable farmers to **increase the economic profitability** of their operations. However, some of our work, like providing Golden Rice seed for free to farmers with low annual incomes is done for the benefit of society.



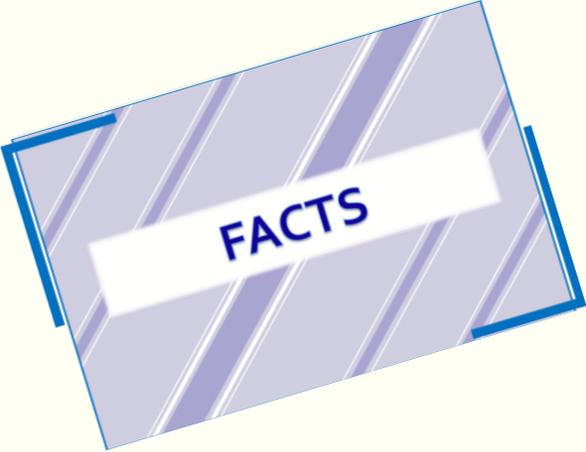
Maria

Genetic engineering

Acceptable uses of genetic engineering

Structured discussion leading to scientific argumentation:
D. Supporting evidence

Evaluate whether genetic engineering of crops can contribute to global food security.



FACTS

Personal - choice

- The Soil Association is a UK-based charity that certifies organic food. Organic foods are free from genetically engineered materials. The Soil Association Organic Market Report states that in the UK sales of organic food grew by 5.3% in 2018 and by 4.5% in 2019. This means that in 2019 organic food accounted for more than 1.5% of food bought in the UK and the market for organic food was worth £2.45 billion [1].
- Those buying organic products often do so because they value organic production systems. A peer-reviewed research study to understand consumer interest in organic production systems found that consumers are *religiously observant, older and of a higher income, and those who claim to be health conscious*.

[1] The Soil Association (2020) Organic Market Report. <https://www.soilassociation.org/certification/the-organic-market-report/#:~:text=Our%202020%20Organic%20Market%20Report,0the%20UK%20today> Accessed 24th July 2020.

[2] Bellows, A. C., Onyango, B., Diamond, J. (2019) Understanding consumer interest in organic food. *Journal of Agricultural and Food Science* 48(1): 1-10.

Economic – profits

- US farmers growing genetically engineered crops have '*generally had favourable economic outcomes*'. The cost-savings for farmers came from areas such as lower production costs, fewer pest problems, reduced use of pesticides and better yields compared with conventional crops. However, there are some farming areas with fewer weed and pest problems that gain little or no economic advantage from genetically engineered crops [1].
- The crops genetically engineered to give resistance to common pests often use a gene from a soil bacterium that produces insecticidal toxins. A soil bacterium called *Bacillus thuringiensis* (Bt) produces crystal proteins which are toxic to many insects. Crop plants have been genetically engineered to contain the gene for the crystal proteins, so that when grown they are toxic to many insects [2].

[1] The National Academies of Science Engineering and Medicine (date) Genetically-engineered crops: past experience and future prospects. Brief report from: <https://www.nap.edu/resource/23395/GE-crops-report-brief.pdf> Accessed 22nd August 2020.

[2] Hellmich, R. L. and Hellmich, A. (2012) Use and impact of Bt maize. *Nature Education Knowledge 3(10)*: 4. (See also: <https://www.nature.com/scitable/knowledge/library/use-and-impact-of-bt-maize-46975413/> Accessed 24th July 2020.)

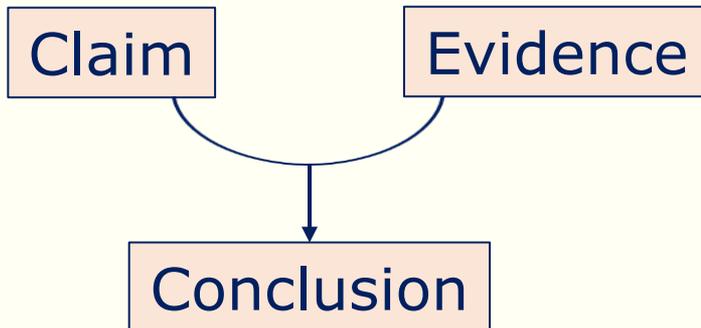
For	Against
Issue FACT	Issue FACT
FACT Issue	FACT Issue

Genetic engineering

Acceptable uses of genetic engineering

Structured discussion leading to scientific argumentation:
E. Conclusion

Evaluate whether genetic engineering of crops can contribute to global food security.



Paragraph 1: State your topic

Write or restate the topic.

For example, 'I am considering the bioethics of whether we should use innovative genetic engineering techniques in crops to increase global food security.'

Paragraph 2: Arguments for

Describe potential benefits, including issues and facts.

For example, 'One argument for using genetic engineering techniques in crops to increase global food security is Evidence that this will help comes from ... who have found that'

Paragraph 3: Arguments against

Describe potential downsides, including issues and facts.

For example, 'One argument against using genetic engineering techniques in crops to increase global food security is Evidence that this is unlikely to help comes from ... who have found that'

Paragraph 4: Conclusion

Draw a reasoned conclusion based on your evaluation of the issues and the facts.

For example, 'I think the strongest argument for using genetic engineering techniques in crops to increase global food security is

In my opinion the strongest argument against using genetic engineering techniques in crops to increase global food security is

The evidence supporting the argument that ... seems weak / unreliable / biased.

After consideration of all issues and facts, I think that genetic engineering of crops could / could not increase global food security.

Genetic engineering

Acceptable uses of genetic engineering

Line of agreement:

What do you think and why?

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... develop new disease-resistant varieties of wheat.

Agree

Disagree

Genetic engineering

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Line of agreement:

What do you think and why?

Scientists should be allowed to use GM technology to...



... develop new wheat varieties with higher yields

Agree

Disagree

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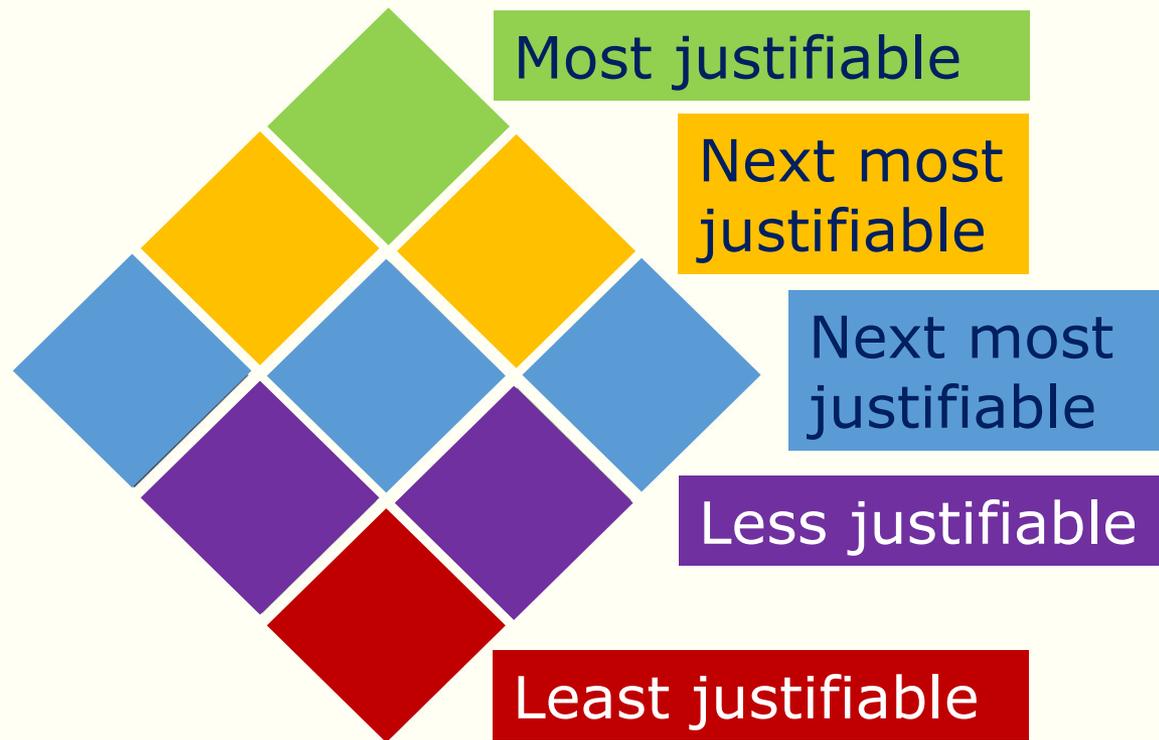
Gene editing

Acceptable uses of gene editing

Diamond 9:
What do you think and why?

What uses of gene editing are ethically justifiable?

Rank the 9 uses of gene editing, balancing the outcomes with the ethics



Gene editing

Acceptable uses of gene editing

Diamond 9:
What do you think and why?

Scientists should be allowed to...

... use gene editing to develop new plant strains in agriculture, for example disease-resistant strains of wheat.



Gene editing

Acceptable uses of gene editing

Diamond 9:

What do you think and why?

Scientists should be allowed to...

... use gene editing to create chickens that produce only female offspring to improve the yield of eggs.



Gene editing

Acceptable uses of gene editing

Diamond 9:
What do you think and why?

Scientists should be allowed to...

... use gene editing without the need to label farm produce from these organisms as genetically modified.



Gene editing

Acceptable uses of gene editing

Diamond 9:

What do you think and why?

Scientists should be allowed to...

... use gene editing to control mosquito populations that spread infectious diseases like malaria, using gene drives.



Gene editing

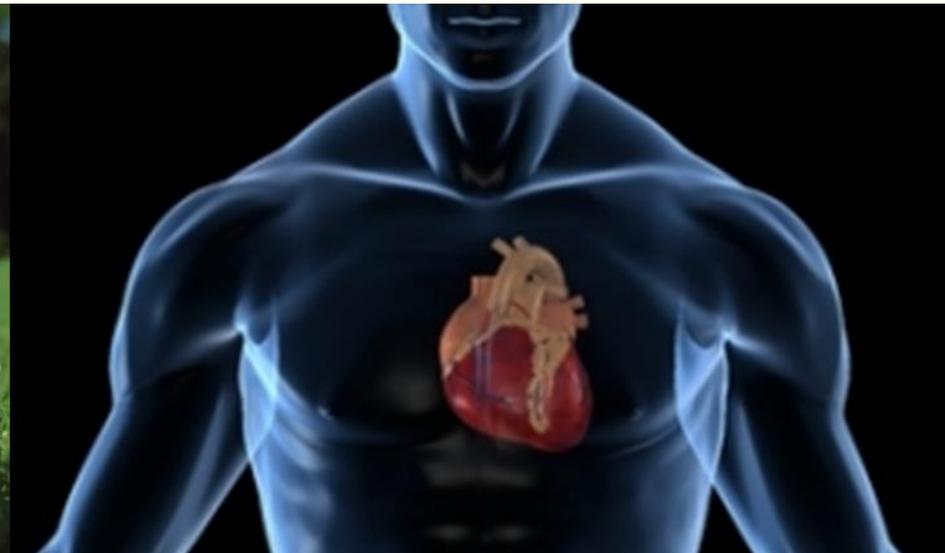
Acceptable uses of gene editing

Diamond 9:

What do you think and why?

Scientists should be allowed to...

... use gene editing to alter pig cells to prevent virus transmission, so that organs can be transplanted from pigs to humans (xenotransplantation).



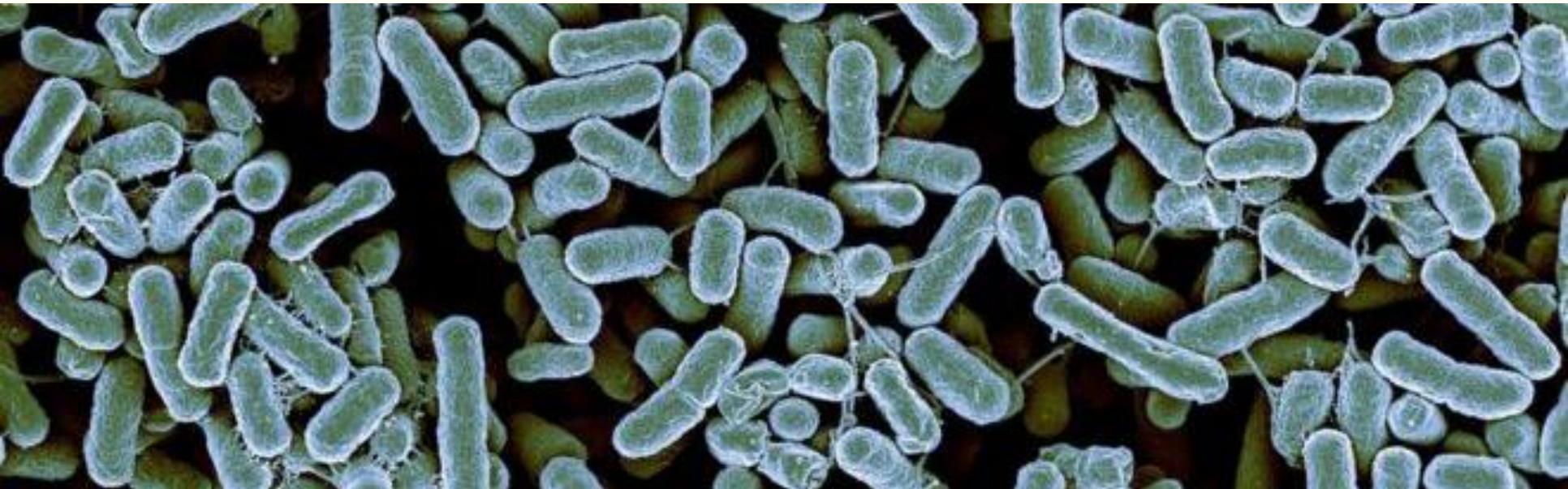
Gene editing

Acceptable uses of gene editing

Diamond 9:
What do you think and why?

Scientists should be allowed to...

... use gene editing to produce bacteria intended to cause a disease outbreak.



Gene editing

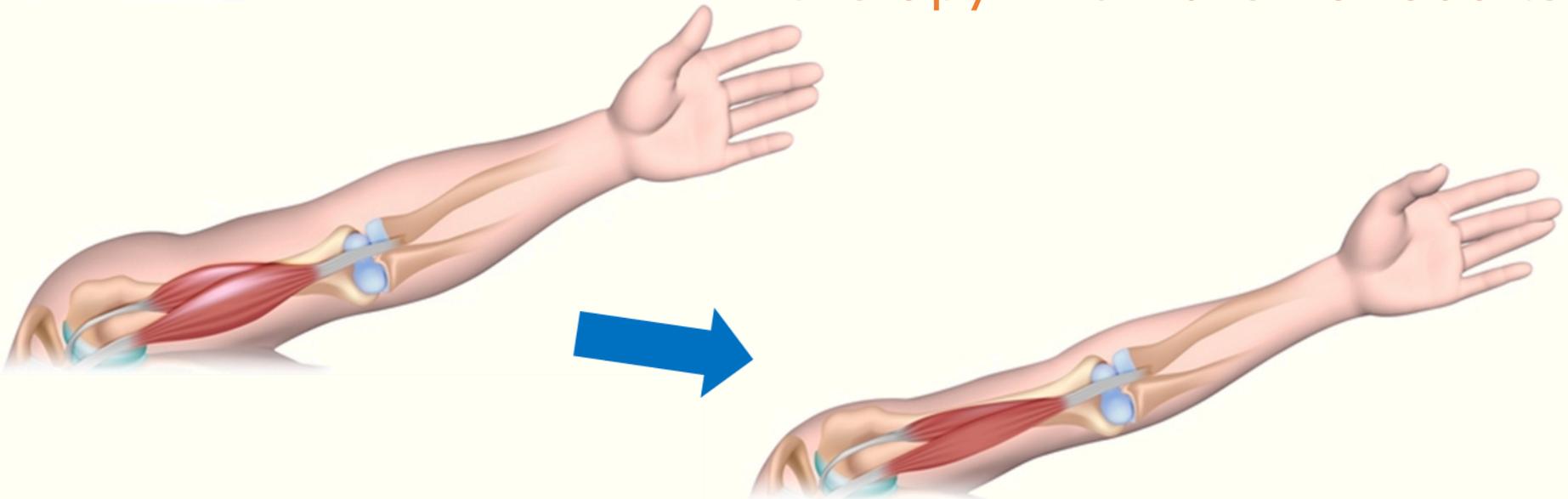
Acceptable uses of gene editing

Diamond 9:

What do you think and why?

Scientists should be allowed to...

... use gene editing to correct the genetic mutation that causes muscular dystrophy through gene therapy in children or adults.



Gene editing

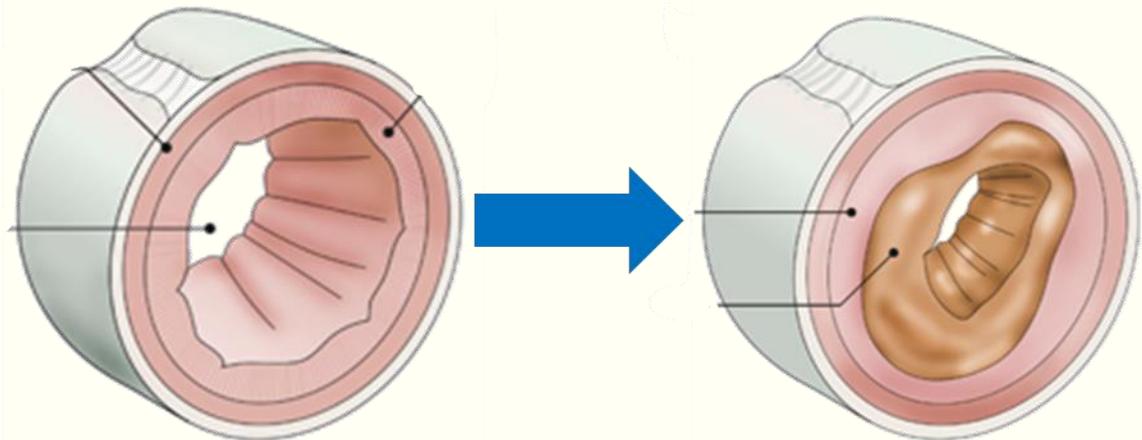
Acceptable uses of gene editing

Diamond 9:

What do you think and why?

Scientists should be allowed to...

... use gene editing to correct the genetic mutation for cystic fibrosis in early stage embryos (pre-implantation genetic manipulation).



Gene editing

Acceptable uses of gene editing

Diamond 9:
What do you think and why?

Scientists should be allowed to...

... use gene editing to enhance athletic ability in early stage embryos (pre-implantation genetic manipulation).



Gene editing

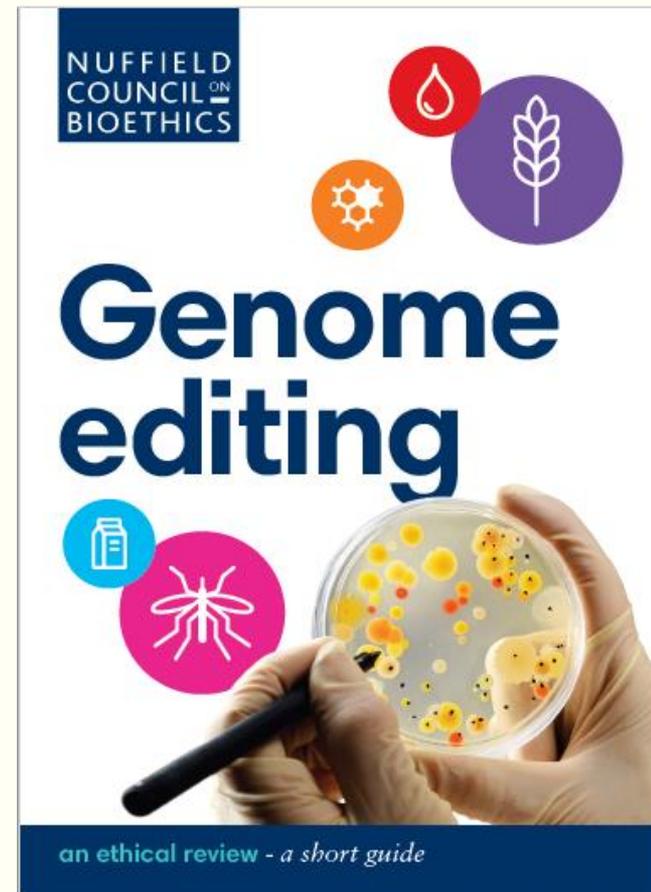
Contributing to the public debate

Submitting responses to public consultations:
Student contribution to societal dialogue

Definitely should
be done again. It
was really good.

Very
interesting
and
worthwhile.

A smashing day! The
discussion was very insightful
and really opened my mind to
the possible future for work in
genetics.



◦ Bioethics in the classroom

Genome sequencing

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Resources

Resources

A selected set from this presentation

If there's something I've talked about you'd like and can't find, please do get in contact 😊

Blog article, Kristen Brown: <http://www.msn.com/en-gb/money/technology/how-dna-testing-botched-my-familys-heritage-and-probably-yours-too/ar-AAv4x44?ocid=se>

SAPS / EIT Food, Genetic engineering resources: <https://www.saps.org.uk/secondary/teaching-resources/1458-selective-breeding-and-genetic-engineering>

Nuffield Council on Bioethics, Genome Editing: [Genome-editing-an-ethical-review-short-guide.pdf](#) (nuffieldbioethics.org)