Genome Editing: Finding a Way Forward

Sarah Norcross, Director

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Everybody's heard about JK

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Basic Understanding of Genome Editing

14 fertility sector patients/practitioners

18 genetic & rare disease patients/carers

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5 day-long workshops
(Plus surveys/webinars with additional larger online group)

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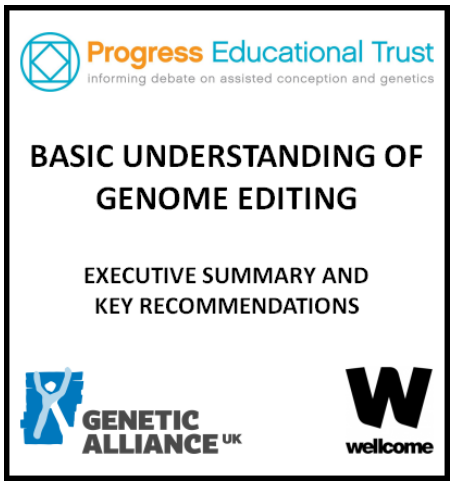
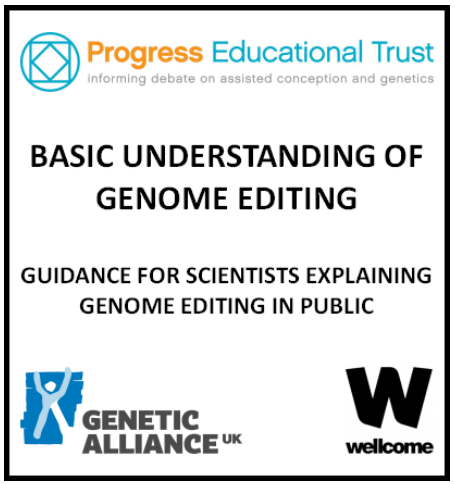
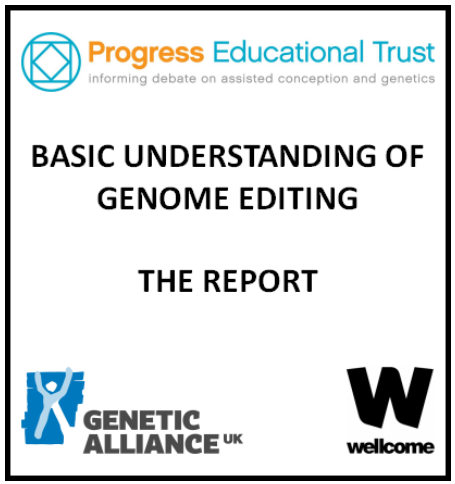
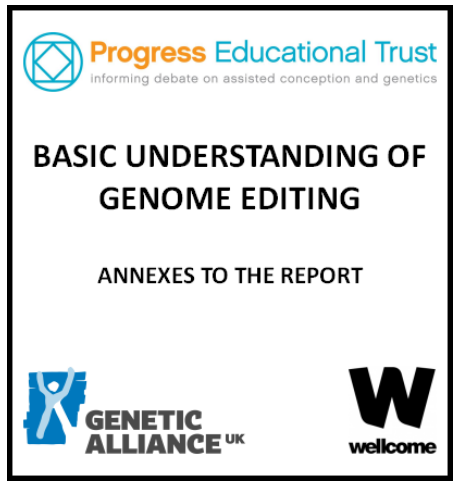
Basic Understanding of Genome Editing









All documents available at www.progress.org.uk/genomeediting

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Recommendations

Before attempting to describe or discuss genome editing, ensure that your audience has some understanding of what a genome is.

Explain this if necessary.

Use the term *'genome editing'* exclusively.

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Other research into public attitudes

A Global Social Media Survey of Attitudes to Human Genome Editing

McCaughey *et al*, ***Cell Stem Cell***, May 2016

SCIENCE AND SOCIETY

U.S. attitudes on human genome editing

Scheufele *et al*, ***Science***, August 2017

Potential uses for genetic technologies: dialogue and engagement research conducted on behalf of the Royal Society

Van Mil *et al*, **Royal Society**, December 2017

Public Views of Gene Editing for Babies Depend on How It Would Be Used

Pew Research Center, July 2018

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Applied ethics exercise

Participants were asked to consider the use of genome editing to achieve each of the following outcomes, all presented with the preceding condition:

'Assuming it is 100% effective and safe for mother and baby...'

- Ensure child does not have gene for Huntington's disease.
- Ensure child has a reduced risk of developing breast cancer.
- Ensure child will develop into a tall adolescent and adult.
- Ensure child will have lifelong resistance to HIV.
- Ensure child will not be short-sighted.
- Ensure child will not develop dyslexia.

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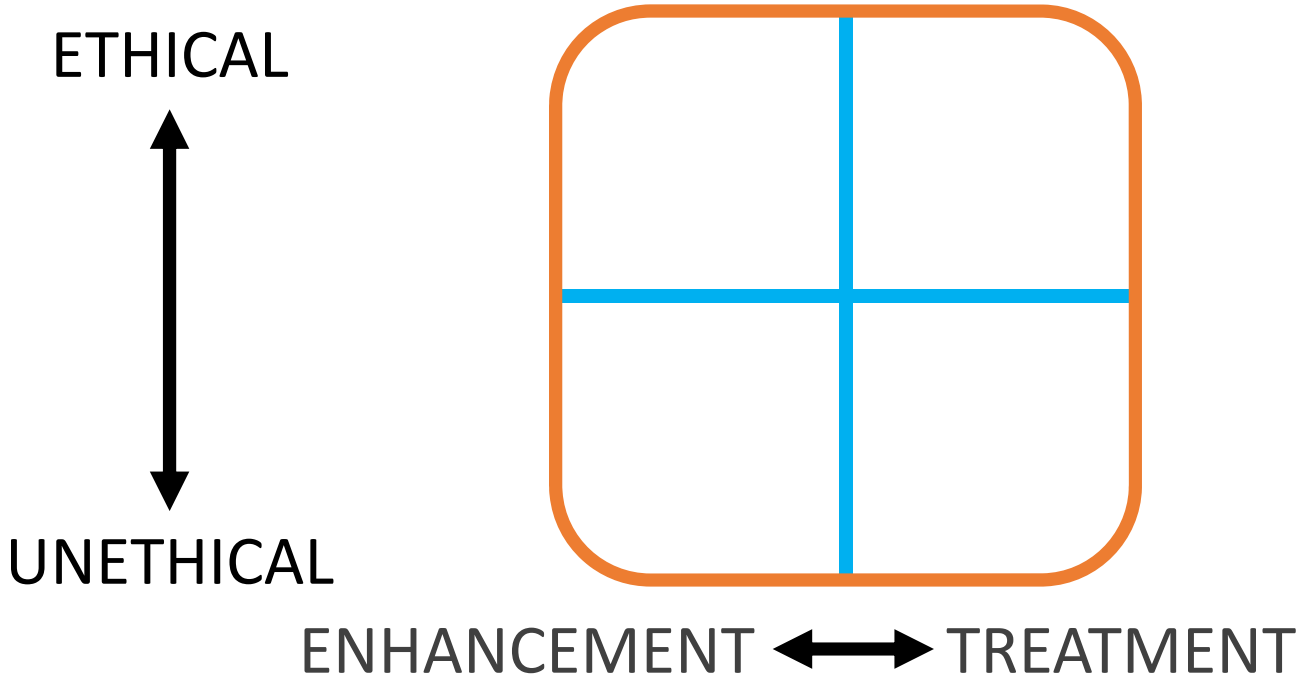
Applied ethics exercise



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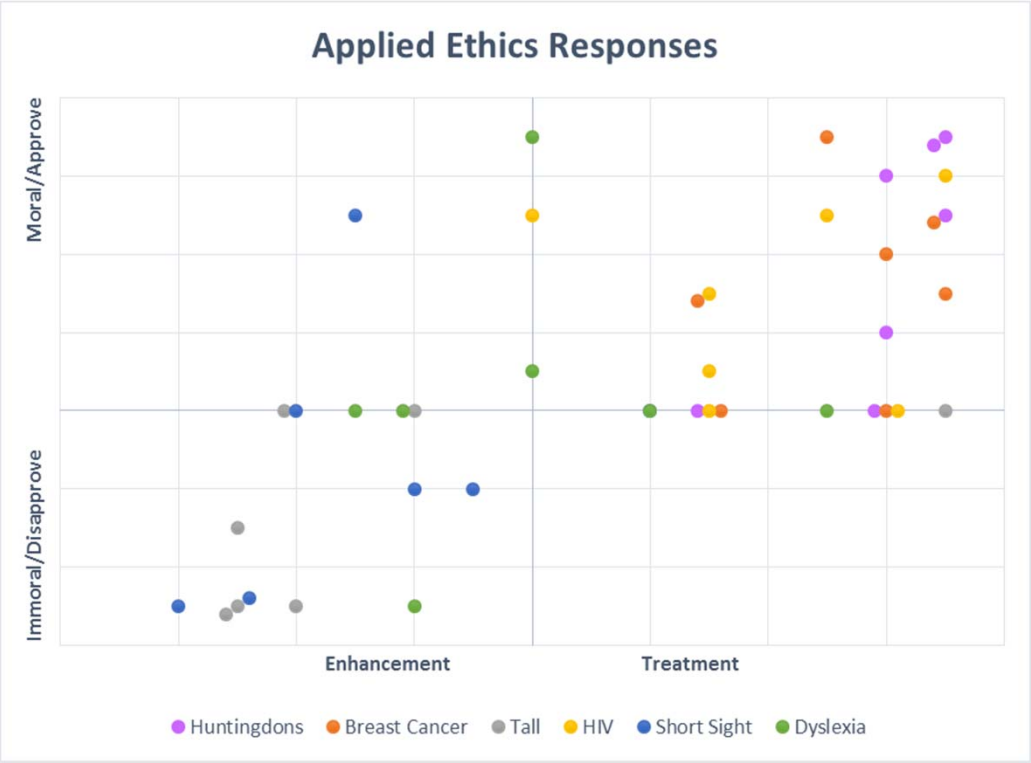
Applied ethics exercise



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Examples of UK legislation

Human Fertilisation and Embryology Act 1990

CHAPTER 37

ARRANGEMENT OF SECTIONS

Principal terms used

Section
1. Meaning of "embryo", "gamete" and associated expressions.
2. Other terms.

Activities governed by the Act

3. Prohibitions in connection with embryos.
4. Prohibitions in connection with gametes.

Human Fertilisation and Embryology Act 2008

CHAPTER 22

PART 1

AMENDMENTS OF THE HUMAN FERTILISATION AND EMBRYOLOGY ACT 1990

Principal terms used in the 1990 Act

1 Meaning of "embryo" and "gamete"
2 Meaning of "nuclear DNA"

Activities governed by the 1990 Act

3 Prohibitions in connection with embryos
4 Prohibitions in connection with genetic material not of human origin

STATUTORY INSTRUMENTS

2015 No. 572

HUMAN FERTILISATION AND EMBRYOLOGY

The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015

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'There are no rules'... or are there?

Neither method has been approved in the US, so Zhang went to Mexico instead, where he says “there are no rules”.

Jessica Hamzelou, ***New Scientist***, September 2016

In conclusion, *under our interpretation of the law and with the available information about the case*, we can assert that Zhang's team broke the Regulations of the General Health Law on Health Research, and that it is very probable that they also broke regulations regarding research on human beings. This conclusion, obviously, stands in stark contrast to Zhang's team's statements about the legality of their research in Mexico.

César Palacios-González and María de Jesús Medina-Arellano, ***Journal of Law and the Biosciences***, December 2017

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How safe is safe?

- What experiments are needed?
- How much must be known about the target gene(s)? Must polygenicity and pleiotropy be accounted for?
- How (if at all) will the accuracy of the edit be assessed in the embryo before it is transferred?
- Who will assess whether all the safety criteria have been met? How will *they* be held to account?

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Potential new UK legislation

- An embryo with an edited genome might become a *'permitted embryo'*. It could therefore be used to establish a pregnancy, in order to avoid *'serious disease'* or similar wording.
- Regulator – presumably the Human Fertilisation and Embryology Authority.
- Clinics would have to apply for a special licence to carry out genome editing work.
- Licensed clinics would then need to apply for a licence to treat on a case-by-case basis. Initially, this would probably be on a very granular basis.
- In time, the rules may evolve to become lass granular, as has happened with PGD.
- In 2009, the regulation of PGD moved from a case-by-case to a condition-by-condition basis. Now, once a condition is authorised for PGD by the HFEA, it is placed on a list. Clinics with appropriate licences can then offer PGD for any condition on the list.

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Frameworks

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Out of frame

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Thanks – especially to our participants

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