



HOW TO TALK ABOUT GENOME EDITING

Involving patients in the discussion

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Supporting families affected by a syndrome without a name



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Campaigning on behalf of all those affected by a rare condition



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PATIENT PERSPECTIVE

Patients affected by a rare genetic condition:

- **welcome the use of genome editing technologies in research and clinical settings**
- **are interested in genome editing technologies, and would like to learn more about them**
- **are clear that use of the technology should be limited to treating medical conditions**
- **believe the benefits of this new and innovative technology far outweighs any potential risks;**
- **want a multiple stakeholder approach to regulatory decisions to ensure ethical use of genome editing technologies, and want to be involved in this process**

GENOME EDITING TECHNOLOGIES

The patient perspective





Progress Educational Trust

informing debate on assisted conception and genetics



GENETIC ALLIANCE^{UK}

W

wellcome





BASIC UNDERSTANDING OF GENOME EDITING

EXECUTIVE SUMMARY AND
KEY RECOMMENDATIONS

BASIC UNDERSTANDING OF GENOME EDITING

GUIDANCE FOR SCIENTISTS EXPLAINING
GENOME EDITING IN PUBLIC

BASIC UNDERSTANDING OF GENOME EDITING

THE REPORT

BASIC UNDERSTANDING OF GENOME EDITING

ANNEXES TO THE REPORT

All documents available at: geneticalliance.org.uk



RECOMMENDATIONS

Be prepared to have to differentiate between genome editing and genome sequencing.

Having made it clear that these are different things, then bring the conversation back to genome editing.

Do not expect complete retention after one explanation of genome editing, no matter how well-received the explanation is.

The message will need to be repeated multiple times, in order to achieve enduring comprehension.



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 and explain genome editing as simply as possible, especially in the first instance.

**Use simple analogies and metaphors:
'[find and replace](#)' and '[cut and paste](#)' work best.**

Do not use potentially confusing alternatives such as 'gene editing', 'genetic editing', 'genomic editing', 'genome engineering' or 'genetic modification'.

Prioritise explaining the use(s) of genome editing over explaining the mechanism(s) via which genome editing works.



NOT ALL GENOME EDITING IS CRISPR . . .

TALENs

Molecular remission of infant B-ALL after infusion of universal TALEN gene-edited CAR T cells

Science Translational Medicine, January 2017

ZFNs

Sangamo claims a major milestone in gene editing, treating first patient with its zinc finger nuclease tech

Endpoints News, November 2017

Base editing

Correction of β -thalassemia mutant by base editor in human embryos

Protein & Cell, November 2017



What is a genome?

What is genome editing?

What can genome editing do?

What is CRISPR?

What is CRISPR/Cas9?



RECOMMENDATIONS

Ensure that the context given for uses of genome editing distinguishes between:

- **Human and other uses**
- **Current and future uses**
- **Uses that are currently allowed and future uses that would require regulatory change**
- **Research and treatment**

When discussing a particular use of genome editing that relates to humans, take particular care to address whether or not it could affect the human germline (either intentionally or inadvertently) and if necessary, explain what ‘germline’ means.



THANK YOU

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 GeneticAllianceUK

 @GeneticAll_UK

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Registered company number: 05772999

