



**BASIC UNDERSTANDING OF GENOME EDITING
EXECUTIVE SUMMARY AND KEY RECOMMENDATIONS**

**Project led by Genetic Alliance UK and the Progress Educational Trust
Supported by the Wellcome Trust**

September 2017



The '**Basic Understanding of Genome Editing**' project was led by **Genetic Alliance UK** and the **Progress Educational Trust (PET)**, and was funded by the **Wellcome Trust**.

The project centred on a series of workshops and online engagement events held between January 2017 and May 2017, which explored what people think and know about genome editing and its implications.

Participants in the project were drawn from the rare disease and (in)fertility communities. These groups are likely to have a particular interest in the development of genome editing technologies, and are also likely to have an important role to play in this development in future.

The project sought to incorporate participants' voices into the development of language and images around genome editing, and to empower participants to discuss genome editing's current uses and future potential.

Key recommendations

The report of the project's findings contains a number of recommendations aimed at people or organisations wishing to discuss genome editing in public. The report's eight key recommendations are as follows.

1. Use the term '*genome editing*' exclusively. Do not use potentially confusing alternatives such as 'gene editing', 'genetic editing', 'genomic editing', 'genome engineering' or 'genetic modification'.
2. Before attempting to describe or discuss genome editing, ensure that your audience has some understanding of what a genome is. Explain this if necessary.
3. Prioritise explaining the use(s) of genome editing over explaining the mechanism(s) via which genome editing works. Deprioritise the term 'CRISPR' – do not use the term interchangeably with genome editing (as CRISPR is just one possible approach to genome editing), and think carefully about whether and when it is necessary to refer to CRISPR at all.
4. Explain genome editing as straightforwardly as possible, certainly in the first instance. Use simple analogies and metaphors – '*find and replace*', '*copy and paste*' and '*cut and paste*' work well, and build on the fact that '*editing*' is already something of a metaphor. Metaphors have their limitations, but they are useful in establishing basic understanding before attempting to go into greater detail.
5. When discussing uses of genome editing, distinguish clearly between:
 - Human and other uses.
 - Current and future uses.
 - Research and treatment.
 - Uses that are currently permitted and uses which would require regulatory change.

It may also be important to distinguish treatment from enhancement, but refrain from suggesting that there is a settled consensus on what this distinction means and where it lies (as that particular debate is ongoing).

6. When discussing a use of genome editing that relates to humans, take particular care to address whether or not it could (intentionally or inadvertently) affect the human germline – in other words, cause a heritable change to the genome.
7. Be prepared to have to differentiate between genome editing and genome sequencing and/or between genome editing and mitochondrial donation, as these are common areas of confusion. Having made it clear that these are different things, then bring the conversation back to genome editing.
8. 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.

Further work

There was insufficient time in this project to fully examine all of the issues of comprehension, language and ethics that our participants wished to discuss.

Genetic Alliance UK, the **Progress Educational Trust** and the participants in our project are all keen to deepen this discussion in further work, and to develop a related set of additional resources. The final chapter of our report outlines possible next steps.