BASIC UNDERSTANDING OF GENOME EDITING
GUIDANCE FOR SCIENTISTS EXPLAINING GENOME EDITING IN PUBLIC

Project led by Genetic Alliance UK and the Progress Educational Trust
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Our aims

Human genome editing is an exciting and rapidly developing area of science. Bodies including UNESCO's International Bioethics Committee, the UK's Royal Society, the USA's National Academies of Sciences and Medicine and the Chinese Academy of Sciences have all called for wide-ranging public engagement on this subject.

However, genome editing and approaches such as CRISPR come atop an existing mountain of genomics- and genetics-related discussion and terminology, and this can present a barrier to public understanding. Our work aims to help scientists communicate on this topic in an accessible way.

Our credentials

In 2017, our charities – **Genetic Alliance UK** and the **Progress Educational Trust** – conducted five day-long workshops plus additional online engagement activities with patients, parents and carers affected by genetic conditions and also with the (in)fertility community. This work was funded by the **Wellcome Trust**.

Our participants – who knew little or nothing about this subject – explored language, imagery and ideas relating to genome editing. They examined media coverage, explanatory videos and other material. They heard from, and put questions to, experts in the science and ethics of genome editing. They even gave their own presentations on genome editing, drawing upon what they had learned.

Participants discussed what they found helpful and what they found unhelpful. The recommendations below summarise what we learned from them.

1. Use the term *'genome editing'* exclusively.

Don't use potentially confusing alternatives such as 'gene editing', 'genetic editing', 'genomic editing', 'genome engineering' or 'genetic modification'. Inconsistency confuses people and lowers their confidence, as they don't know whether these terms refer to the same technology or to different technologies.

An advantage of using the term *'genome editing'* is that it has wide scientific applicability. Even an edit to a single gene (or part of a gene) can be said to change an entire genome, and can still involve an entire genome being searched by a guide molecule.

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.

The term *'genome'* isn't as well known or well understood as you might assume. Furthermore, even people who are familiar with the term can sometimes get confused about what it means. If you offer a brief explanation or reminder of what a genome is, *before* you discuss genome editing, then people are far more likely to understand you.

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

   Deprioritise the term 'CRISPR'. Don't use the term interchangeably with genome editing, and think carefully about whether and when it's necessary to refer to CRISPR at all. Of course there's a lot of excitement about CRISPR, and for good reason, but it wasn't the first approach to genome editing and it may not be the last.

   Likewise, deprioritise the term 'CRISPR/Cas9' even further, and don't use that term interchangeably with either 'CRISPR' or 'genome editing'. Cas9 isn't the only nuclease that can be used for CRISPR, and it may be superseded in future.

   It's best to talk about genome editing more broadly, at least to begin with. By way of analogy, when genome sequencing is discussed in public people don't tend to focus on the method of sequencing or other such detailed mechanics.

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.**

   The reason these metaphors work well is because they build on the fact that *'editing'* is already something of a metaphor, and there are already well-established metaphors which liken genes to text and genomes to books.

   Other popular metaphors include *'satnav'* as the guide molecule that directs a nuclease to the relevant part of the genome, and *'scissors'* as the nuclease which cuts DNA at the required site in the genome. People don't find these metaphors quite as clear and useful as *'find and replace', 'copy and paste'* and *'cut and paste'*, but it's still worth being familiar with them because they're in circulation and so people may have already encountered them.

   All metaphors have their limitations, and even the best metaphors will fail to capture particular aspects of genome editing. But metaphors are still 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.**

   Genome editing has a vast range of current and possible future uses. It's important to make clear distinctions between these uses, otherwise people can easily get confused. If you want to explain genome editing as it relates to humans, then this is such a rich and challenging subject that non-human uses may deserve little more than a passing mention.

   It's sometimes important to distinguish use of genome editing for treatment from use of genome editing for enhancement. However, you should be careful not to claim that there's a settled consensus on what this distinction means and where it lies. There are different views on the matter, both among specialists and among the public, and debate is still ongoing.

6. **When discussing a use of genome editing that relates to humans, take particular care to address whether or not it could (either intentionally or inadvertently) affect the human germline – in other words, cause a heritable change to the genome.**

   Somatic genome editing results in changes that are *not* heritable by the next generation. Germline genome editing results in changes that *are* heritable by the next generation. This distinction is of vital importance in science, ethics, law and policy.

   In many countries (including the UK), germline genome editing is prohibited in humans except in a research context (where it is used only on human germ cells, or on human embryos that will never be used to establish a pregnancy).

   Despite all of this, it's not always easy for people to understand the somatic/germline distinction. Nor is it easy for people to understand the reasons why specialists consider this distinction so important. You therefore need to take care to draw attention to this distinction and explain it.

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.**

   People can often get genome editing mixed up with genome sequencing (determining the order of nucleotide bases in a genome) or with mitochondrial donation (IVF techniques to avoid the transmission of mitochondrial disease when conceiving a child). The confusion arises partly because all of these things have recently been in the news at the same time, with the news coverage sometimes using the same terminology and ideas.

   It's important to resolve this sort of confusion whenever it arises. In order to clarify how genome editing is distinct from other technologies, you should make sure that you're able to explain genome sequencing and mitochondrial donation succinctly. Note that some revision may be in order (even if you're an expert in this field!) – mitochondrial donation in particular is a complex topic, involving different aspects and approaches which can be difficult to grasp and/or difficult to convey clearly to the public.

   Having said that, it's equally important not to become so distracted by these other subjects that discussion of genome editing is derailed. Having made it clear that genome sequencing and/or mitochondrial donation are very different from genome editing, then steer the conversation back to genome editing.

8. **Don't 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.**

   People are undoubtedly interested in genome editing, but the subject isn't straightforward to understand. Even after people have had the subject explained to them and feel confident that they've grasped it, they may find it difficult to retain their understanding.

   You should therefore seek opportunities to repeat your explanations, so that people's understanding of genome editing can endure and grow.