BASIC UNDERSTANDING OF GENOME EDITING
ANNEXES TO THE REPORT

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

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CONTENTS

ANNEX A: GUIDANCE FOR SCIENTISTS EXPLAINING GENOME EDITING IN PUBLIC

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.

ANNEX B: MODERATOR/SPEAKER BIOGRAPHIES

Moderators

Both of the moderators of our workshops combined experience in science with experience in performance and comedy. Timandra Harkness moderated the PET Group's workshops, Helen Pilcher moderated the Genetic Alliance UK Group's workshops, and for the joint workshop – where the two groups were brought together – they moderated in tandem.

Timandra Harkness is a science writer and broadcaster and is Visiting Fellow in Big Data, Information Rights and Public Engagement at the University of Winchester. She is producer and presenter of a number of science-related programmes on BBC Radio 4, including the series *FutureProofing* – for which she has interviewed Jennifer Doudna, pioneer of the CRISPR approach to genome editing – and the documentaries *Data, Data Everywhere* and *Personality Politics*. She is also a stand-up comedian, and author of the book *Big Data: Does Size Matter?*.

Dr Helen Pilcher is a science writer and broadcaster, with a PhD in stem cell biology. She writes for publications including *BBC Focus*, *BBC Wildlife*, the *Guardian* newspaper and *New Scientist* magazine, and she is a regular host of the UK's Maths Inspiration programme of events for teenagers. Previously she was Science in Society Manager at the Royal Society, a Science Reporter at *Nature*, and a Senior Scientist at the stem cell research company ReNeuron. She is a stand-up comedian, and author of the book *Bring Back the King: The New Science of De-Extinction*.

Speakers

Each workshop included, partway through the day, a presentation from an expert speaker who then responded to questions from participants. The five speakers are as follows – we are extremely grateful to them for donating their time and expertise.

Dr John Parrington is Associate Professor of Cellular and Molecular Pharmacology at the University of Oxford. His research focuses on the molecular mechanisms of reproduction and early embryogenesis, the role of calcium signals in mediating key physiological events, and genomic and proteomic approaches to understanding cell signalling. He is author of the popular science books *Redesigning Life: How Genome Editing Will Transform the World* and *The Deeper Genome: Why There Is More to the Human Genome than Meets the Eye*.

Dr Güneş Taylor is a Research Fellow in the laboratory of Professor Robin Lovell-Badge at the Francis Crick Institute, where she uses genome editing in her research. She originally studied at the University of Nottingham, and went on to acquire her PhD at the University of Oxford's Weatherall Institute of Molecular Medicine. She has carried out science communication work for the Science Council, I'm a Scientist Get Me Out Of Here and the Cheltenham Science Festival, and she has debated genome editing at the Battle of Ideas festival and the Festival of Genomics.

Dr Andy Greenfield is Programme Leader in Mammalian Sexual Development at MRC Harwell – the Medical Research Council's international centre for mouse genetics – where his research focuses on Disorders of sex development. He is also a Member of the Human Fertilisation and Embryology Authority – the UK's regulator of fertility treatment and embryo research – and a Member of the Nuffield Council on Bioethics. He was Chair of the Working Group which produced the Nuffield Council on Bioethics report *Genome Editing: An Ethical Review*.

Dr Chris Gyngell is a Research Fellow at the Oxford Uehiro Centre for Practical Ethics and at the Oxford Centre for Neuroethics. He has a PhD in Philosophy – his thesis was on *Human Enhancement and Human Diversity: The Need For a Coordinated Approach to Enhancement Technologies* – as well as degrees in Applied Ethics and Human Genetics. He is currently investigating the ethical and legal implications of new reproductive technologies, including genome editing, as leader of a research project entitled *Selecting, Creating and Modifying Embryos*.

Dr Cathy Herbrand is a Senior Lecturer at De Montfort University's Centre for Reproduction Research, and is a Member of the Belgian Advisory Committee on Bioethics. She has a PhD in Sociology from the Free University of Brussels, and she has researched and taught at institutions including King's College London, the London School of Economics and Political Science, and the University of Ottawa. She is leader of the *MITOFAMILY* study, which is investigating genetics, reproduction and biotechnology in the context of mitochondrial disorders.

ANNEX C: GENOMICS QUIZ RESULTS

Question	Answer	Correct Answers			
		All Workshops	Genetic Alliance UK	PET	Online
A genome is a small unit of DNA.	False	18/25 72%	9/14 64%	7/8 88%	49/86 57%
A genome is our genetic code.	True	23/25 92%	13/14 93%	7/8 88%	78/86 91%
A genome is formed of four letters – A, T, C, G.	True	17/25 68%	8/14 57%	7/8 88%	48/86 56%
A genome is written in a code called DNA.	True	23/25 92%	14/14 100%	6/8 75%	71/86 83%
A genome is different in different cells of the body.	False (except for in specialist contexts, we say an individual has a single genome and it is the same in all cells of the body)	18/25 72%	11/14 79%	4/8 50%	60/86 70%
Genome editing is a research tool to edit the genome.	True	24/25 96%	13/14 93%	8/8 100%	65/86 76%
Genome editing is being used in the clinic to correct genetic mistakes in human embryos.	False	17/25 68%	9/14 64%	6/8 75%	28/86 33%
Genome editing is permitted in human embryos for research purposes only.	True	20/25 80%	11/14 79%	6/8 75%	–
Genome editing is a technique to treat mitochondrial diseases.	False (but could become true in future)	6/25 24%	1/14 7%	4/8 50%	32/86 37%

Genome editing is a technique for preventing mitochondrial diseases by creating a 'three-person baby'.	False	13/25 52%	7/14 50%	4/8 50%	–
Genome editing has been used to cure leukaemia in the UK.	True	134/25 52%	6/14 43%	4/8 50%	34/86 40%
Genome editing is a tool to read DNA and find where genetic mistakes are.	False (genome sequencing is usually used for this purpose)	7/25 28%	3/14 21%	2/8 25%	22/86 27%
Genome editing is the research tool behind the 100,000 Genomes Project.	False	11/25 44%	3/14 21%	5/8 63%	–
Overall Score		65%	59%	67%	57%

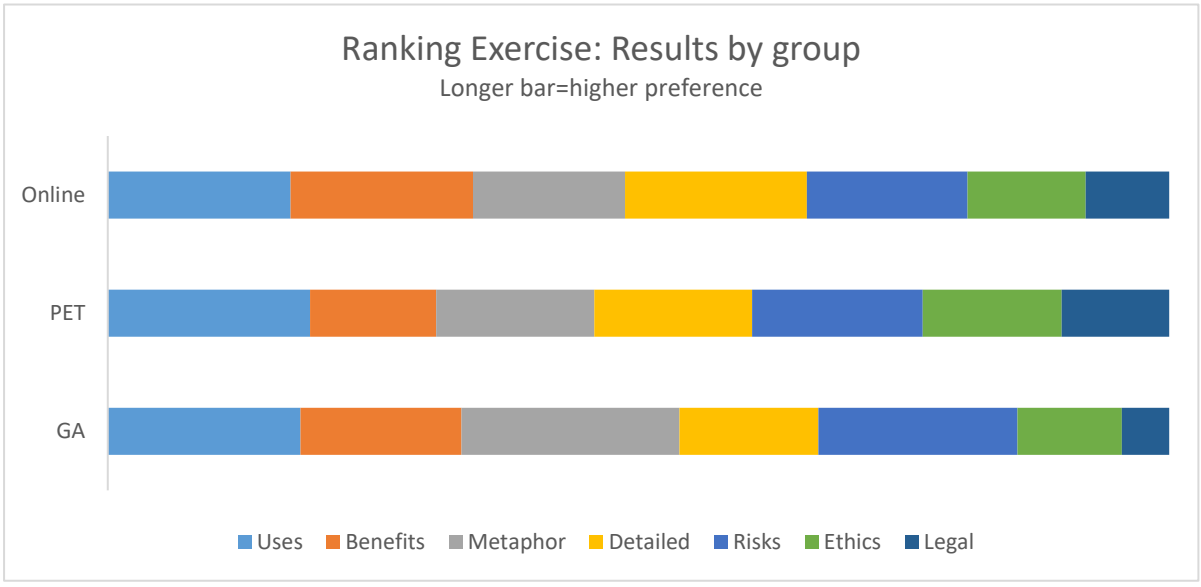
ANNEX D: RANKING EXERCISE

Instructions

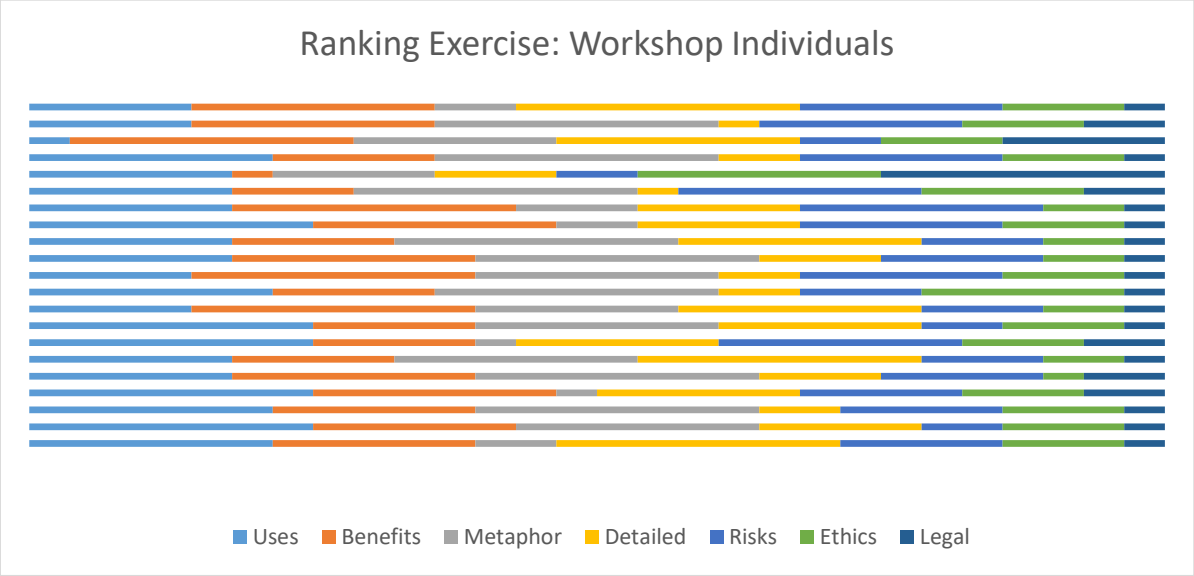
Participants were told: *'Imagine you are reading an article or watching a video reporting on genome editing. Below are some of the things that you might find, or want to find, in the article or video. If the reporter could only include some of this information, which parts would you consider most important?'*

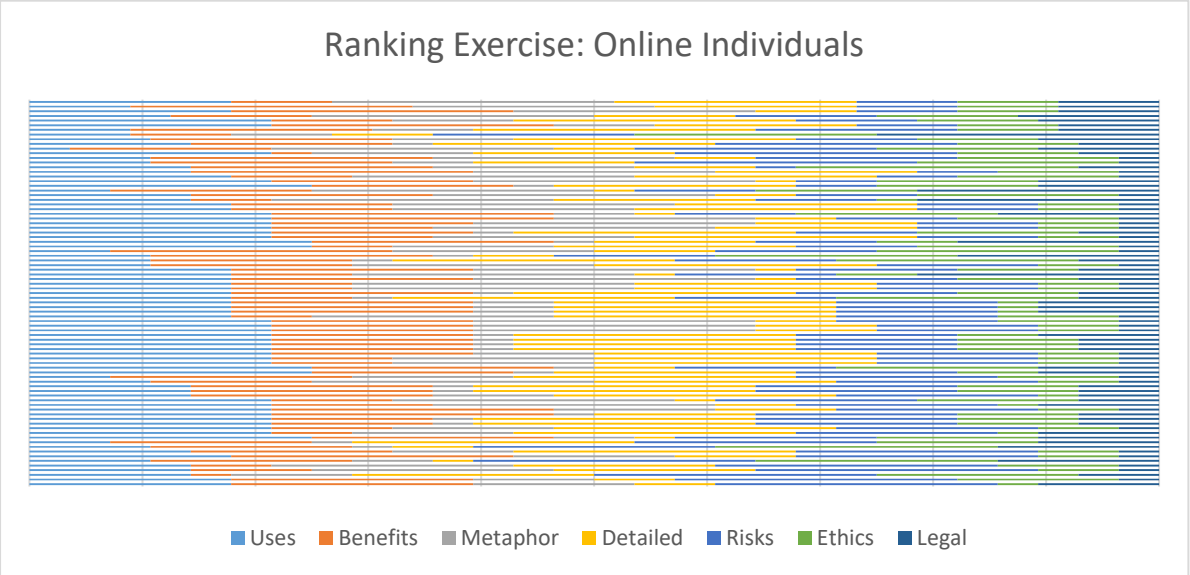
Results by group

	Genetic Alliance UK Group	PET Group	Online Group
A metaphor describing how genome editing works	3	1	4
A detailed explanation of how genome editing works	4	6	1
Current uses of genome editing	1	= 3	2
Risks of using genome editing	5	= 3	5
Potential benefits arising from the use of genome editing	2	2	3
Ethical implications of using genome editing	6	5	6
Legal aspects of genome editing	7	7	7



Individual results





ANNEX E: PARTICIPANTS' NAÏVE VIEWS IN THEIR OWN WORDS

What is a genome?

- Hear it all the time but cannot define.
- Unsure if bigger or smaller than a gene.
- Bigger than an exome.
- Gene, genome, chromosome, exome – not sure how they relate to each other.
- Genetic code of an organism – entire recipe.
- Roadmap, recipe, shopping list.
- Contains information or is information?

What is genome editing?

- 'Messing with nature.' *(comment from participant's partner)*
- Putting things in, taking things out. Cutting bits out, adding bits in.
- Altering things in our bodies.
- Altering out biological makeup.
- Related to PGD/mito.
- For example, in a recipe swap salt for sugar.
- For example, Chernobyl – is that editing?
    - Yes – genetic alteration is passed on to offspring.
    - No – someone didn't do it to you.
- Editing as a word.
- Positive connotations – improvement.
- Neutral.
- Implications so broad may include both positive and negative.
- Genome editing – word 'genome' pulls in ethics, religion, range of views.
- Editing implies control.
- Editing implies an irreversible change.
    - Very precise and targeted.
    - SNPs.
    - Looking for cures.
    - External event done to genome for greater good.
    - Interfering with overall structure.

How might genome editing be used?

- Improve quality of life/extend life.

- Need to learn lessons from gene therapy.
- In embryos.
- During pregnancy.
- In adults.
- Genetic illnesses.
- Cancer treatment.
- Humans.
- Animals.
- Unicorns.
- Food.
- To the advantage of humanity.
- Improve life and health.
- Eliminate disease.
- Control populations.
- Eliminate disease (or cure disease).
- Mito.
- Disabilities? More complex.
- Eugenics.
- Super-race.
- Superficial characteristics.

How far along is genome editing? Have patients been treated?

- *Show of hands – has it been done in...*
    - Human tissue in the lab? *(all raised their hands)*
    - A born person? *(a few raised their hands)*
    - A born person in the UK? *(none raised their hands)*
- Some countries are already doing it.
- Has medical progress already edited the human race?
- Abroad maybe?
- Only just approved so not in the UK.
- Maybe in a research project?
- Early days – we don't know what is going on.
- Not sure if it's in use but probably not.
- Yes overseas but not in the UK.
- Not far off.

Positive themes

- Open debate/discussion.
- Improvement in science.
    - Pioneer.
    - Upgrade.
- Potential therapeutic benefits.
    - Cure for muscular dystrophy.
    - Cancer's weakness.

Negative themes

- Uncertainty.
- Designer, curate.
    - Commodification.
    - Superficial.
    - Eugenics.
- Language.
    - Shocks.
    - Fears.
    - 'Scare quotes.'
- Lack or regulation or technology in wrong hands.

Terms the participants had googled

- RNA.
- Nucleases.
- CRISPR.
- TALENs.
- ZFNs (zinc finger nucleases).

ANNEX F: SUMMARIES OF PARTICIPANTS' PRESENTATIONS

PET Group

Team 1

Target audience – Metro/Evening Standard readers

- Cancer.
- New tech Cas9 offers hope for cancer and genetic disorders.
- What is a genome? Instruction manual – grow and develop.
- Typos > genetic diseases.
- Cas9 is Satnav, finds way to typo and fixes it.
- Used – cure little girl of leukemia. Proposed – human embryos.
- More work to do before can become mainstream.

Feedback: Clear, informative, hopeful, balanced, human interest. Ethical and social.

Team 2

Target audience – Dinner party

Speaker 1

- Genome editing.
- What is a genome? Instruction manual.
- Tells cells how to grow and fix itself.
- Made of DNA. Recipe.
- Bits of DNA not right – genetic disorders.
- Protein-enzyme thing can go and find specific bits of DNA.

Speaker 2

- Applications.
- Mainly in research, animal models.
- Used in patients – cells outside the body. Child, leukaemia.
- Licence granted for embryos – excess from IVF.
- HFEA (part of government) makes sure only within law – up to 14 days only.
- Ethical debates around it.

Feedback: Conversation is a great medium – can ask questions back and forth.

Team 3

Target audience – Group of genetic condition patients

Speaker 1

- Human genome.
- Complete set of genetic instructions – all living organisms.

- 50% genes from each parent. All information to grow and develop.
- Recent ability to map genomes.
- Genes influence all organs and body.
- Gene defects – inherited, or damage from environmental factors in embryo or later life, for example cancer.
- Improve health and welfare, predict and prevent.

Speaker 2

- Gene editing.
- Change genes.
- For example Cas9.
- CRISPR is a protein that is able to get inside cell and guides to right place.
- Cas9 – molecular scissors, stop gene working or put correct.
- Metaphor – Thames water van and plumber named Cas.
- The CRISPR satnav in his van tells him where he needs to go for his job.
- Cas the plumber with his pipe-cutters cuts broken pipe and replaces with new piece.

Feedback: On top of all technical terms, great metaphor, well-pitched for audience.

Team 4

Upper primary school pupils (aged about 10)

- People get sick – have you heard of cancer?
- New technology – medical science to help.
- What is a gene? Our body is made up of cells, genes are the recipe in each cell which makes up what we are.
- Speaker 1's shoes and necklace match Speaker 2's earrings and bag. They use this as a metaphor – editing Speaker 2's outfit. Explain that you can't just 'yank' shoes off – you have to do it with precision.
- Sickness and genetics – some people are born with or develop issues where part of their genes aren't working well.
- Cas9 is a way of very precisely removing or changing genes to make people healthier.

Feedback: Visual aspect, well-pitched for children, asked questions – interactive.

Genetic Alliance UK Group

Team 1

Target audience – Evening class, 'How to make/repair a human'

- What are humans made of? Cells, formed at conception.
- Contains an instruction manual to make and repair a human embryo.
- DNA normally thought as a template, but DNA is a script – different directors will produce different versions of *Romeo and Juliet* even though the script is the same.
- DNA is formed of letters ATCG.

- Physical structure of DNA – as a zip or a ladder.
- 'The fat sat on the mat....' 'The bat.…' Wrong instruction, may or may not have an effect, error in script might lead to a genetic condition.
- 'Genome editing is all about replacing errors in the DNA script.'
- 'We are very much at the Gutenberg stage of genome editing.' CRISPR will develop a long way.

Team 2

Target audience – Facebook video (voiceover), general Facebook users

- Human genome – set of genetic instructions.
- Sometimes instructions are not quite correct.
- Small changes to the genome can make a big difference.
- Genome editing 'is using a tool named CRISPR to find the part of the genome that needs to be changed and then using another tool called Cas9 to cut out the area'.
- Can alter the instructions or erase them all together.
- Can be used to treat/cure genetic conditions.
- Is it safe? Are there risks? Developed with safety and ethical concerns in mind.
- Potential for misuse – cosmetic use, designer babies.
- Expensive to develop – cost to implement and develop is irrelevant given the potential of the technology.

Team 3

Target audience – Animated video

- Genes passed down from parents (inheritance patterns) – how mutated versus normal versions of the genes are passed down in generations.
- These mutations can cause conditions – add a list of conditions.
- Genome editing – happening in the lab, scientists are currently researching.
- Genome editing – searching for mutations (search, cut and paste visual).
- This can then be used in the patient affected by the condition.
- For more information click here (this is to be a series of videos), first video for someone who has just been diagnosed or the parent of someone who has been diagnosed, to be shared by support groups for people who might benefit (sickle cell, thalassemia, cystic fibrosis).

Team 4

Target audience – Teenagers, presentation in a workshop/science fair

- Any living organism is made of building blocks – cells – in organs, muscle, blood.
- Like LEGO needs instructions, we have our genome – info needed to build and maintain a living organism.
- Instructions that determine looks and how we relate to environment are coded in the DNA – the chemical language of the genome.

- The DNA is in all the cells of the body. Sometimes instructions contain errors that can make organisms malfunction – either at the start or later in life.
- Genome editing – correct the information, modify superficial features, find cure for disease.
- For example, using enzymes and molecules to find the faulty pieces of DNA – one tool called CRISPR/Cas9.
- CRISPR is like a guide/satnav that instructs the Cas9 to find and replace the wrong information. (Use visual activities like building blocks, or microscope.)

Team 5

Target audience – Conversation with seven-year-old

- Genome editing? Do you know what a genome is?
- Set of instructions that puts your body together. We all have a genome – me, you, cat, plants.
- Set of instructions example – LEGO kit – the booklet shows you how to put it together.
- Genome is made of DNA – like the building blocks of the LEGO.
- Genome editing – make changes, for example the colour of the bricks, or the size, or the wheels, or turn an aeroplane into a helicopter.
- Can I make changes? Very specific and precise changes – for example, key for vehicle – it will only fit a certain vehicle.
- Are we changing things to make them better? Yes, to treat people who are poorly, or to stop them getting poorly in the first place.
- Application – for patients.

Team 6

Target audience – Secondary school students, raising awareness as part of Rare Disease Week

- Intro to rare conditions, list of rare conditions.
- Genetics role in rare diseases – genetic information as instructions.
- Assume DNA known from science lessons. Genome – complete set of DNA to grow and develop.
- Genome editing – history of selective breeding/trait selection in crops and livestock.
- Human genome editing – already happened, used to cure conditions like leukaemia.
- CRISPR/Cas9 advances genetic research and treatment – quicker, easier and cheaper.
- May change lives affected by genetic conditions and future generations.
- Change/fix defective genetic information – two stages.
- Find mutation where wrong info is causing disease. (CRISPR – synthesised chemical that locates the genetic information.)
- Alter/remove/add info within that section of DNA. (Cas9 cuts DNA at the right place – genetic scissors.)
- Influencing genome can change how cells behave, even cure genetic conditions.

- Technology being used to understand how cells respond to treatment and to advance research all over the world.

ANNEX G: SELECTION OF RESPONSES TO HEADLINES

Participants were asked to categorise and respond to headlines, and to highlight the key words and phrases in each headline that had prompted their reaction.

Positive

- Future of human gene editing to be decided at ***landmark summit*** *(discussion and debate taking place)*
- The new gene-***editing*** technique that reveals ***cancer's*** weakness *(therapeutic benefit)*
- CRISPR is ***getting better****.* Now it's time to ask the hard ethical questions.
- ***WTF*** is CRISPR? *(presumably the article will explain what it is)*
- Scientists must be part of the ***ethical debate*** on human genetics
- Patients ***favour changing the genes*** **of the** ***next generation*** with ***CRISPR***
- GM embryos: time for ***ethics*** debate, say ***scientists***
- Gene editing technique could transform future
- CRISPR: is it a good idea to ***'upgrade'*** our DNA?
- How CRISPR could lead to a ***cure for muscular dystrophy***
- CRISPR: Chinese scientists to ***pioneer*** gene-editing ***trial on humans*** *(pioneer positive)*

Neutral

- Why ***banning*** CRISPR gene editing would be ***unnecessarily cautious***
- First genetically modified humans could exist within two years
- How to ***(really)*** engineer a human baby
- Designer genes
- Future of human gene editing to be decided at ***landmark summit*** *(was public excluded from debate?)*

Negative

- Designer genes *(designer baby?)*
- CRISPR: Chinese scientists to pioneer gene-editing trial on humans *(negative for UK, not at forefront?)*
- Concerns about lack of regulation and ethical oversight in other jurisdictions
- How to ***curate*** the human fate
- Rules to let scientists 'edit genes' and experiment on human embryos sparks ***designer baby fears***
- ***Designer baby fears*** after genetic modification of human embryos gets green light
- Genetic scientists ***could*** try to create a unicorn – or a dragon, report ***warns***
- ***'Frankentinies' fear****:* embryos to be genetically modified in UK for first time
- China ***shocks*** world by genetically modifying human embryos

- '***Any idiot*** can do it.' Genome editor CRISPR could put mutant mice in everyone's reach
- ***'Improving'*** humans with customised genes sparks debate among scientists *(scare quotes around word)*

ANNEX H: SELECTION OF WRITTEN RESPONSES TO IMAGES

Participants collaborated on the following written responses in pairs.

Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Looks rather mangy. Presuming it is Dolly the sheep. Interested – keen to find out more.

Caption revealed – ***What a long way we have come since Dolly the Sheep***

Did the caption surprise you?

No.

What thoughts or feelings are prompted in you by the image and caption combined?

Not clear what article is about – not clear in 'what' we have come a long way. Not with cloning but further progress in genetics.

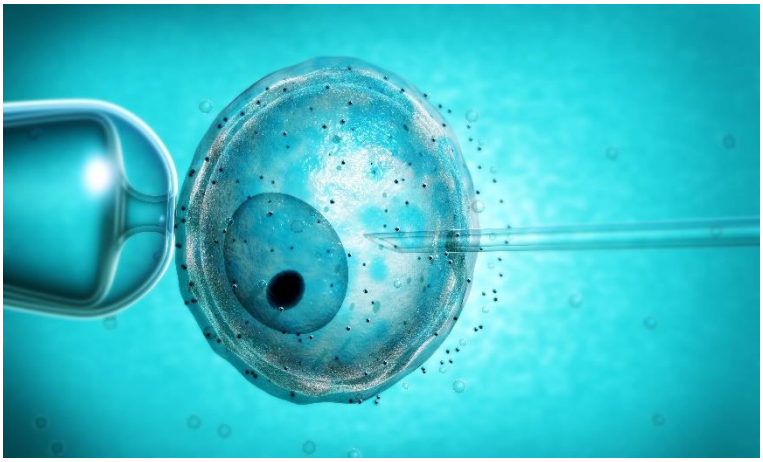
Headline revealed – ***It's time society discussed the ethical issues raised by the gene revolution***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

Bring in human perspective? Use of term 'gene' or 'genetic' more fitting? Expectation of broad general coverage with focus on specific ethical issues.



Do you think this image would help you understand genome editing?

[No answer.]

How does this image make you feel?

About creating human life.

Caption revealed – ***Chinese scientists have reported that they have carried out the world's first experiments to genetically engineer a human embryo***

Did the caption surprise you?

No.

What thoughts or feelings are prompted in you by the image and caption combined?

Interesting.

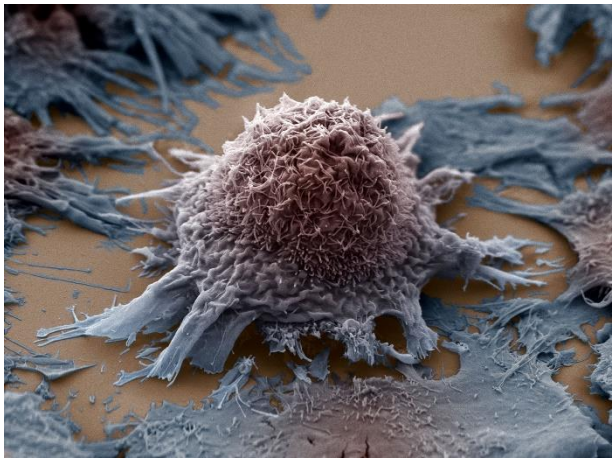
Headline revealed – ***China shocks world by genetically engineering human embryos***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

[No answer.]



Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

1) That it is going to be a science-loaded article.
2) I like that image, it interests me.

Caption revealed – ***An expert panel in the US has given the green light the use a precise gene editing technique to boost the effectiveness of cancer treatments. If approved by the FDA, the trials could see 18 cancer patients treated with their own edited immune cells.***

Did the caption surprise you?

1) Yes.
2) No.

What thoughts or feelings are prompted in you by the image and caption combined?

Really interested. Want to know more. Hopeful message but not sensationalist. Caution expressed with clear comment on waiting for FDA approval. Only 18 patients so not claiming to cure all cancer

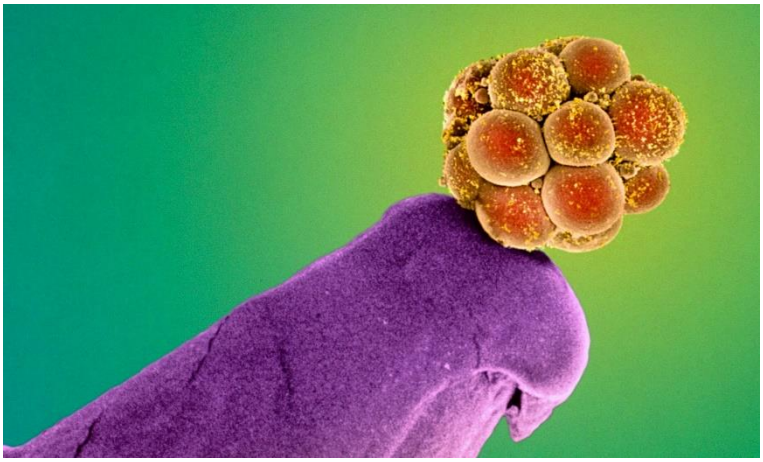
Headline revealed – ***World's first gene editing trial on HUMANS gets the green light. Controversial tests could help treat cancer patients.***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

The use of the word 'controversial' changes the feel of the article. The previous caption was positive, however the use of 'controversial' makes me worry, as if they already know that people won't like it and it changes to feel of the article. I feel that it might make me annoyed. 'Trial' is good as implies testing, but is 'HUMANS' in capitals trying to cause alarm?



Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Intrigued. No idea what this is. Is it a parrot? Are those mouldy peaches?

Caption revealed – ***A human embryo at the 16-cell stage on the tip of a pin. Germline editing would transform the process of embryo screening.***

Did the caption surprise you?

No.

What thoughts or feelings are prompted in you by the image and caption combined?

Doesn't look like a pin. Is scale even relevant to this article? Or – is pin helpful to remind people how early this is in development?

Headline revealed – ***CRISPR: is it a good idea to 'upgrade' our DNA?***

Would the image, caption and headline combined make you want to read more?

No.

What preconceptions have you formed about the article that follows?

Not what I want to read. 'Upgrade' makes me think a cosmetic improvement. Non-essential 'upgrade'.

Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Fantasy fairytale non-scientific.

Caption revealed – ***Chilling***

Did the caption surprise you?

Yes.

What thoughts or feelings are prompted in you by the image and caption combined?

Confused. Why?

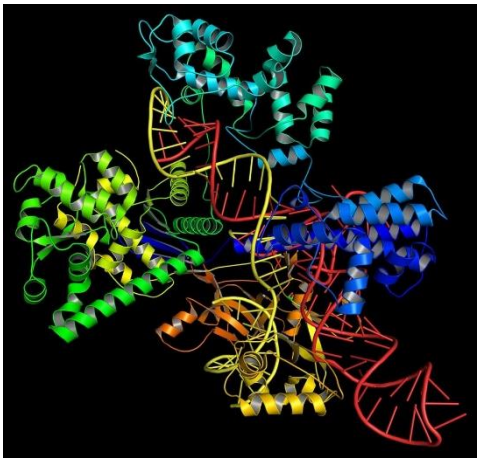
Headline revealed – ***Genetic scientists could try to create a unicorn – or a dragon, report warns***

Would the image, caption and headline combined make you want to read more?

No.

What preconceptions have you formed about the article that follows?

Genome editing should be for serious diseases, not to create unicorns and dragons. Cross. Lightens the actual issues of genetic disorders.



Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Like a piece of art.

Caption revealed – ***The Cas9 protein uses a molecular structure – a system for editing, regulating and targeting genomes***

Did the caption surprise you?

No.

What thoughts or feelings are prompted in you by the image and caption combined?

Sounds a bit scientific to arts/layperson like me.

Headline revealed – ***CRISPR: Chinese scientists to pioneer gene-editing trial on humans***

Would the image, caption and headline combined make you want to read more?

No.

What preconceptions have you formed about the article that follows?

Again, sounds a bit sciencey for me.

Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

[No answer.]

Caption revealed – ***Brave new world: scientists can modify human embryos***

Did the caption surprise you?

No.

What thoughts or feelings are prompted in you by the image and caption combined?

That thing that looks like a toy must be a DNA helix.

Headline revealed – ***Designer baby fears after genetic modification of human embryos gets green light***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

It is happening/has happened. This is real.

Do you think this image would help you understand genome editing?

NO.

How does this image make you feel?

Not an enormous amount. Hello mouse!

Caption revealed – ***Rudolf Jaenisch made the first transgenic mouse in 1974 and has pioneered the engineering of CRISPR mice.***

Did the caption surprise you?

Yes.

What thoughts or feelings are prompted in you by the image and caption combined?

Makes more sense but still confused by the caption (transgenic/CRISPR mice).

Headline revealed – ***'Any idiot can do it.' Genome editor CRISPR could put mutant mice in everyone's reach.***

Would the image, caption and headline combined make you want to read more?

No.

What preconceptions have you formed about the article that follows?

Feels sensationalist. I don't believe it.

Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Cute, nothing particular, baby pictures emotive.

Caption revealed – ***Every year an estimated 7.9 million children are born with a serious birth defect of genetic or partially genetic origin***

Did the caption surprise you?

No.

What thoughts or feelings are prompted in you by the image and caption combined?

Very good picture to accompany caption (or other way around). Clever use of image.

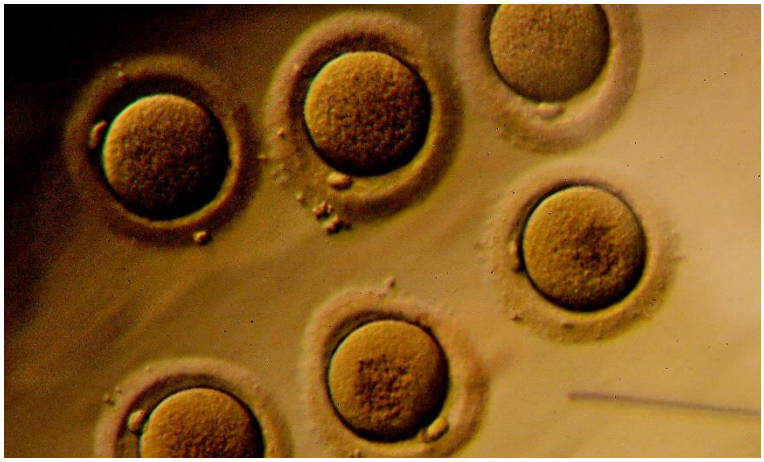
Headline revealed – ***Why human gene editing must not be stopped***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

Pro gene editing. Sensible article. Well-informed and clearly written.



Do you think this image would help you understand genome editing?

No – not alone.

How does this image make you feel?

Aware that the article will be related to embryos? Could be fertility. In a lab.

Caption revealed – ***Human embryos on a petri dish are viewed through a microscope***

Did the caption surprise you?

No.

What thoughts or feelings are prompted in you by the image and caption combined?

Amazing that we can create and see human embryos. Are they embryos (look like eggs)? Is this research or treatment?

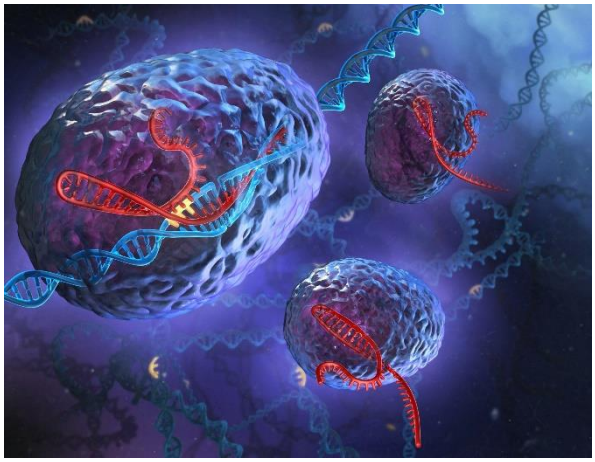
Headline revealed – ***Scientists must be part of the ethical debate on human genetics***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

Will be scientific with more information. Agree that debate should be ongoing. Suggests we are just working up to this which is incorrect. Research has to have ethical approval. Possibly wouldn't learn a lot but very interested to read it.



Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Strange image. Too vague. Bit sci-fi. Bottom of sea? Space? Who knows?

Caption revealed – ***Artist's depiction of the CRISPR system in action***

Did the caption surprise you?

Yes.

What thoughts or feelings are prompted in you by the image and caption combined?

Complete confusion. Image doesn't seem to show anything related to the CRISPR system. Where are the scissors?

Headline revealed – ***UCSD, Isis Pharm advance CRISPR gene editing***

Would the image, caption and headline combined make you want to read more?

No.

What preconceptions have you formed about the article that follows?

I won't understand it. I have no idea really what its about.

Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Child with feeding problem of some sort that could be for a number of reasons. Concerned about the health of the child, as smiling despite her 'condition'.

Caption revealed – ***Layla Richards***

Did the caption surprise you?

No.

What thoughts or feelings are prompted in you by the image and caption combined?

Tells us nothing apart from the child's name. Personal story – concern and sadness as health-related problem.

Headline revealed – ***Dawn of gene-editing medicine?***

Would the image, caption and headline combined make you want to read more?

[No answer.]

What preconceptions have you formed about the article that follows?

That child either has genetic condition or has had some form of gene editing treatment.

Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Nothing. Quite cute.

Caption revealed – ***A genetically modified pet pig developed in China. Chinese scientists made headlines earlier this year after editing the genomes of human embryos.***

Did the caption surprise you?

1) Yes.
2) No.

What thoughts or feelings are prompted in you by the image and caption combined?

Because of context of workshop we kind of expected it. Shock and feeling that the cute image draws you in and then the caption changes the meaning because it is not a cute pet pig but a genetically modified experiment. Caption is so much more loaded than the picture.

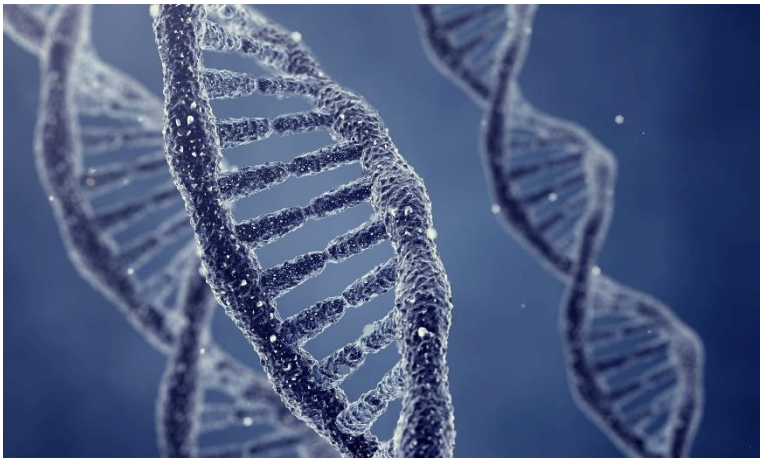
Headline revealed – ***Top biologists debate ban on gene editing***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

The article will be a debate. Scientists with differing opinions. Probably controversial issues raised. Hope that it would be balanced.



Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Looks a bit 'coral like'. Computer generated.

Caption revealed – ***Should humans take control of their genetic fate, and rewrite the DNA of future generations?***

Did the caption surprise you?

No.

What thoughts or feelings are prompted in you by the image and caption combined?

Image scientific, caption sensational, 'rewriting the future' dramatic rather than balanced. Presumption that this can be achieved.

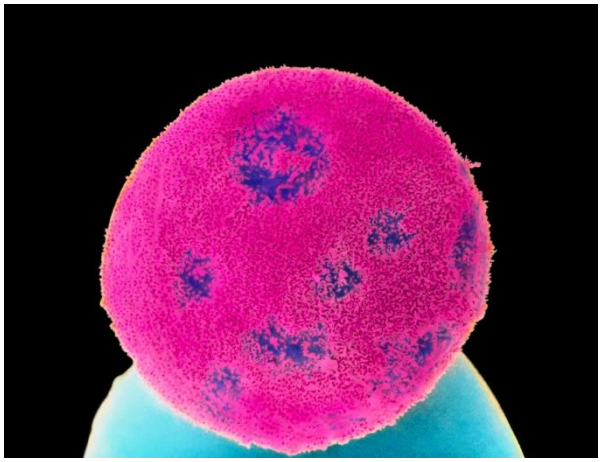
Headline revealed – ***Future of human gene editing to be decided at landmark summit***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

Sensational and unrealistic. Alarming suggestion that a group of people could even presume to make far-reaching decisions. Multidisciplinary. Would expect lots of factual information.



Do you think this image would help you understand genome editing?

No.

How does this image make you feel?

Pretty. Nothing.

Caption revealed – ***Human embryos are at the centre of a debate over the ethics of genome editing***

Did the caption surprise you?

1) Yes.
2) No.

What thoughts or feelings are prompted in you by the image and caption combined?

Caption very neutral – not obvious as to whether it's a positive or negative thing. Use of 'human embryos' terminology is provoking me as it's a controversial topic.

Headline revealed – ***Genome editing: seven facts about a revolutionary technology***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

That it would be quick and easy to get the information without reading the whole article. Feel that it would be a very scientific factual report without any controversial claims or strong opinions either way. 'Revolutionary' – positive term rather than negative (rather than use of 'controversial').

Do you think this image would help you understand genome editing?

[No answer.]

How does this image make you feel?

1) They seem happy, positive picture.
2) Nothing.

Caption revealed – ***Jeff Carroll and his wife, Megan. Carroll has a genetic mutation that means he will develop Huntington's disease.***

Did the caption surprise you?

1) Yes.
2) No.

What thoughts or feelings are prompted in you by the image and caption combined?

Sympathy. Not as happy as previously thought.

Headline revealed – ***Patients favour changing the genes of the next generation with CRISPR***

Would the image, caption and headline combined make you want to read more?

Yes.

What preconceptions have you formed about the article that follows?

1) Image plus caption would have an understanding audience vs headline alone.
2) I think all three together will make the article very interesting to me as it will give a personal perspective on this technique. Not just the science but it will put it into context and how it would help specific families.