CUT + PASTE EXHIBITION

LARGE PRINT BOOK

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See differently

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Plan of Cut + Paste Exhibition

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Glazed wall

Column

Cafe seating area

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AT Accessible toilet
E Entrance/exit
K Cafe kiosk
T Toilets
1 Zone 1
2 Zone 2
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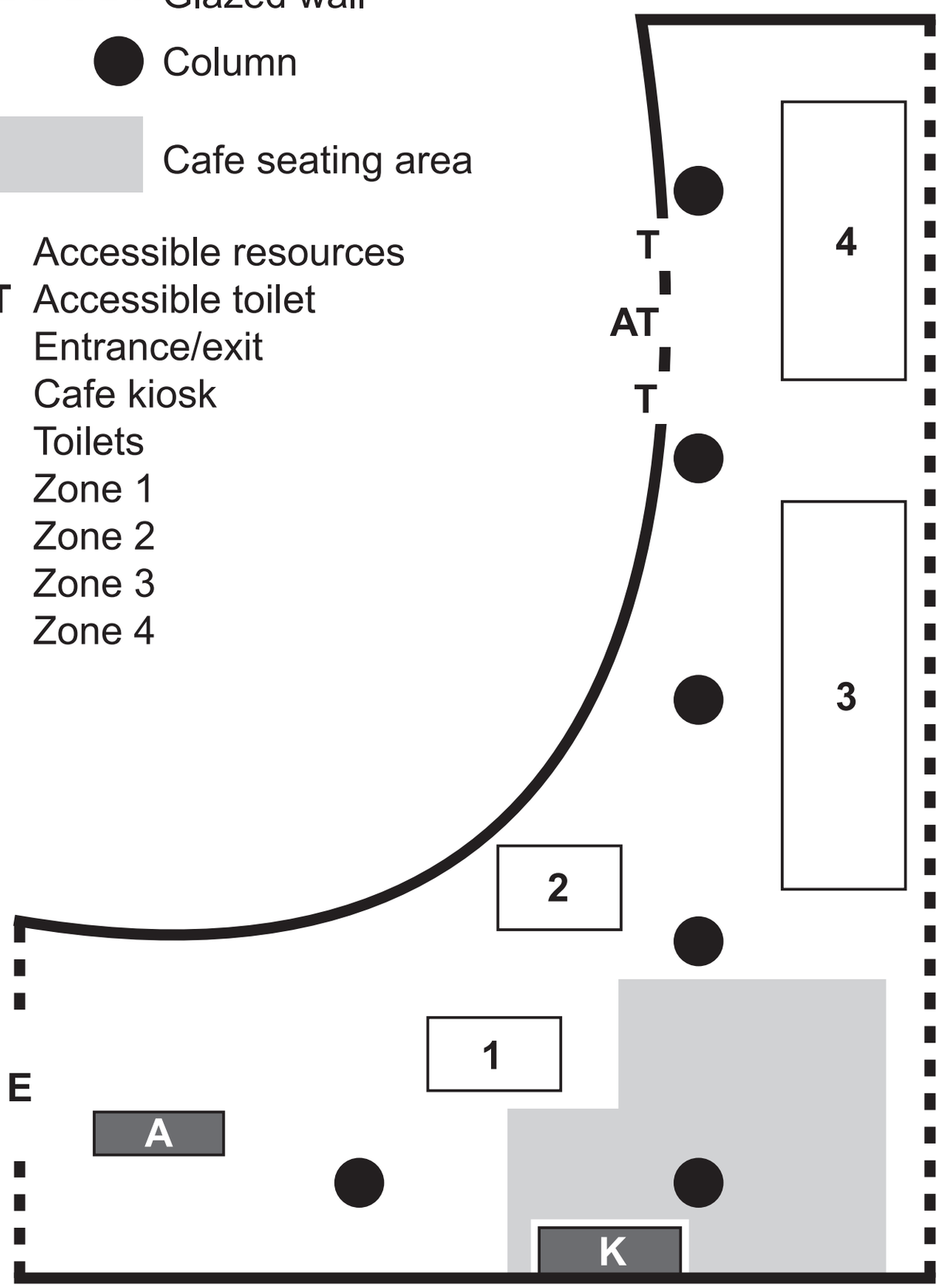

INTRODUCTION

Cut + Paste Exhibition *Explore the building blocks of life*

“Who are you?”

It’s a simple question with a complicated answer.

Inside almost every cell in your body there is a unique set of instructions called your genome, which is made up of DNA.

It is a kind of manual, setting out many details from the shape of your hands and feet and the colour of your eyes and hair to your preference for sweet or bitter foods. In fact, every living thing on the planet - plants and animals - has its own set of instructions.

Of course, that’s not the whole story. The world around you - and everything that happens to you during your life - helps to shape who you are. But your genome is the important starting point for making you *you*.

New genome editing tools are changing how science is done at places like the Crick, allowing scientists to alter DNA more quickly, more easily and more accurately.

These tools are improving scientists’ ability to study what different parts of DNA do, how these affect our growth and development, and our chances of developing specific health problems. Genome editing helps research the significance of genetic variants, to treat conditions and diseases, and to understand and alter our environment.

Genome editing technologies hold extraordinary potential to improve human health and the world around us. But using these new tools brings all sorts of important ethical questions and concerns along with them. Which diseases should we try to cure? What is the difference between treating (or avoiding) a genetic condition, and enhancement? How much about ourselves should we change?

How should we use these tools, how should they be regulated, and who should decide?

In Cut + Paste you're invited to think about these questions, ask your own, and have your say.

Please note that the zone numbers referenced are for the purpose of the large print book only and are not advertised in the gallery.

Questions scattered throughout exhibition:

- If you could change one thing about yourself, what would it be?
- Is there any feature you would rather not pass on? Why?
- Genome editing has the power to shape the future. Whose vision of the future should it be?
- Which human characteristics are ‘desirable’? Why?
- **Somatic** genome editing of a person’s body cells, where the edits are **not** passed onto future generations, could be used to treat people living with certain genetic conditions. How do you feel about this?
- **Heritable** genome editing of embryos, or of cells that give rise to sperm or eggs, might alter characteristics that could be passed onto future generations. How do you feel about this?
- Genome editing could be used to avoid or treat ‘severe’ conditions. Who gets to decide which conditions are ‘severe’ and should be treated?
- Genome editing could enable parents to alter the DNA of embryos, so that their future children could avoid a particular genetic condition. What do you think about this?
- Should genome editing be used to create human ‘enhancements’? How can ‘enhancement’ be defined?
- If genome editing in plants or animals could help to reduce hunger or malnutrition, would you support it?

ZONE 1: What are you made of?

The average human being is made of more than 30 trillion cells. These form your skin, bones, brain, and every other bit of your body. And in almost all of your cells there is a copy of your unique instruction manual: your genome. To understand how this manual can be edited by ‘cutting and pasting’, first it’s helpful to know how we are constructed…

What are you made of?

- Your genome is made up of DNA - long chains of chemicals arranged in a sequence that are tightly coiled into a spiral called a double helix. Sections of these chemical sequences are called genes, and they control different elements of your body’s growth and development, and how your body functions.
- Half of your DNA comes from your mother and half from your father - this is why you inherit similarities in the way you look, but also why some diseases or conditions can be passed on from one generation to the next.
- Your body is constantly copying its genome as it grows and replaces cells. Very occasionally, errors occur during the copying process which can lead to diseases such as cancer.

- Each strand of coiled DNA is called a chromosome. Most humans have 46 chromosomes arranged in 23 pairs. Almost every cell type in the body has a full set of these chromosome pairs in its nucleus, the cell's 'control centre'.

What makes you you?

- Your genome can influence many things about you from the colour of your hair and the shape of your toes to how likely you are to develop certain diseases. But is there more to you than your DNA?
- There are lots of other factors that can influence how you develop, from the food you eat (or your mother ate while you were in the womb) to how much you exercise; whether you drink or smoke; and the climate that you live in.
- We all 'enhance' ourselves to some degree: whether it is through education, using drugs such as caffeine to increase alertness, wearing make-up, working out, or even undergoing surgery to change the body.

What is genome editing?

- Humans have been shaping the genomes of plants and animals for centuries by carefully selecting and breeding certain species that have desirable traits. This has been carried out with animals such as dogs, cattle or sheep, and with plants such as tomatoes, wheat or corn. Genome editing tools allow scientists to introduce faster changes with a wider range of possibilities.
- One of these genome editing tools is called CRISPR (*pronounced "crisper"*). CRISPR can be programmed to recognize and 'cut' a snippet of DNA and 'paste' in a new piece. The edit can be made on a very tiny or a much larger section of DNA. This editing process is very useful for scientists trying to work out what certain genes or sections of DNA do. Their discoveries can help in the treatment of diseases such as cystic fibrosis and some cancers, as well as the development of new ways to fight malaria by editing mosquito genomes.
- Today, around 80% of labs at the Crick use new cutting and pasting tools to target and edit specific parts of the genomes of different organisms - including animals, fungi and bacteria. These tools support the scientists' research in a variety of ways. One example used by some labs at the Crick involves genome editing zebrafish. As young zebrafish are transparent, their major organs are very visible, which makes it a really useful model organism for understanding cell development. To identify and highlight specific organs and cell types, genome editing is used to insert light-emitting genes from other organisms, such as jellyfish,

into the zebrafish embryo. This means researchers can ‘tag’ particular cells so they emit different coloured light, and they can analyse them more easily and in real time.

- A person’s genome can be edited to treat a specific disease - this is called a ‘somatic’ edit. For example, somatic editing is being trialled to treat people with sickle cell disease. The treatment will not change the genome of any future children they may have. Changes to the genome that *can* be passed on are carried out on egg and sperm cells or very early embryos, and they are called ‘heritable’ edits. Heritable genome editing is not currently legal in the UK.
- Genome editing tools are advancing all the time and in the future they could allow us to edit the genomes of plants, animals and humans more quickly, easily and accurately than ever before.

ZONE 2: PASS IT DOWN

We share all sorts of attributes with our families: some are understood to be the product of inherited genes, like hair type or eye shape. Other traits, like the ability to sing, are thought to be the product of interactions between genes and our environment, upbringing and life experiences. Many other aspects of who we are may be influenced in some way by our genes, but are still not well understood.

Pass It Down invites you to think about your traits, tastes and talents. What have you inherited? What would you hope to pass on?

There are 3 trays on the table-top containing magnetic objects that can be touched (list of objects below). There are two magnetic boards in the shape of a gift, one board is located behind the trays and the other is located at the end of the table.

The objects are divided into traits, tastes and talents and a prompt asks you to select what you would pass on. You can choose up to six objects from the table that represent what you have inherited and that you would like to pass on, and add them to one of the ‘gift’ shaped magnetic boards. If you want to add your own, use a blank board and one of the pens provided. Take a picture and share on Twitter or Instagram with the hashtag #CutAndPaste.

Please note that when you arrive at the activity some of the objects may already be attached to the magnetic board, please feel free to remove these and select your own.

Object List

Tastes:

Lollipop (wood & plastic) – Sweet tooth

Chilli (wood & plastic) – Spicey foods

Paw (wood & fake fur) - Animal lover

Suitcase (cardboard) - Globe trotter

Book shape (wood) - Book worm

Ball shape (wood) - Sports fan

Traits:

Smiley face (wood) – Dimples

Moon (plastic) - Night Owl

Half sun with rays (wood)- Early Bird

Comb (plastic) – Hair type

Haha! Speech bubble (Wood) - Sense of Humour

Heart (wood & fake fur) - Compassion

Talents:

Record (plastic) – Musicality

Frying pan (metal & plastic) - Master Chef

Artists palette (wood) - Creativity

Star (wood & plastic) - Entertainer

Spanner (wood) - Fixer

Petri Dish (plastic) - Science Whizz

Sometimes what we inherit includes a genetic variant or condition that we may not wish to pass on.

Genome editing for treatments

Currently, somatic genome editing treatments (which only affect the body of the person being treated, and not future generations) are being trialled for a number of conditions that are caused by variants in specific single genes. These include blood diseases like sickle cell disease and haemophilia B, some inherited forms of sight loss, leukaemia and several other cancers.

It is not yet possible to use genome editing as a treatment or cure for conditions that can be caused by the combined effect of multiple gene variants, such as heart disease and diabetes.

Genome editing for reproduction

Currently it is not legal in the UK to use heritable genome editing (where the edit would affect all future generations) to alter an early embryo, eggs or sperm to prevent passing on a particular genetic condition. If a person wishes to avoid passing on a particular genetic condition, they may use genetic testing. One type is prenatal testing, which is carried out on a pregnant person or the embryo they are carrying.

Another type is pre-implantation genetic testing, which can only be used to test for conditions where one specific gene is the known cause. To use this, prospective parents create a number of embryos using in-vitro fertilisation (IVF). Pre-implantation genetic testing then allows the selection of embryos that do not carry the specific gene variant that causes the inherited condition. Those embryos are then transferred to the parent's womb.

Genome editing for 'enhancement'

Could genome editing be used to 'enhance' the human body, by editing in traits that are considered 'desirable'? Even if it were legal (which it isn't in the UK and many other countries), heritable genome editing is not currently capable of allowing people to 'design' babies, and it isn't likely to be in the near future. Many human traits are shaped by a complex combination of factors, which may include several or dozens of genes, as well as the impacts of nutrition, environment, lifestyle and life experiences.

ZONE 3: ROLL THE DICE

At times, life can feel like a game of chance. From the DNA we were born with, to all the twists and turns along the way that will affect who we are and how we live, so much is beyond our control. Genome editing offers us the possibility of changing the hand that nature - and other complex forces - may have dealt us. How might we use it to change ourselves and the world around us?

Genome editing can be used in many different ways - and new applications are being developed all the time. Play the game to find out more and have your say:

In this zone there is a large colourful dice on a round rug which can be rolled to randomly select one of six topic cards, each topic has a colour and picture that matches a side of the dice.

The text from the topic cards is below in this book, with the associated coloured headings.

Once you have read the information you can collect a ping pong ball which matches the colour. Answer the **Final Question** and decide what you think by placing it in one of five funnels labelled:

No Way!

- **I don't think so**
- **Hmmm… Not Sure**
- **Okay with me**

Bring it on!

TOPIC CARDS:

ORANGE: Plant power

Should genome editing be used to help solve global health issues?

Poor diets - lacking in protein, energy, iron, zinc, vitamin A and iodine - cause the deaths of around 30,000 people each day globally.

Rice is an important food eaten by more than 3.5 billion people around the world. Scientists have been trying to improve its nutrition for years through complex and time-consuming analysis and selective breeding programmes.

In the late 1990s, scientists used a forerunner of genome editing to create golden rice, rich in a plant pigment called beta-carotene, which the body converts to vitamin A. Lack of vitamin A is estimated to kill more than 670,000 children under five every year and causes an eye problem called night blindness. Due to strict regulations around the development and testing of genetically altered foods, it wasn't until 2018 that the US, Australia, Canada and New Zealand approved golden rice for human consumption.

Genome editing offers a more efficient and cost-effective way of making crops that are resistant to disease and changes in climate, and provide better nutrition.

Talking points…

- Supporters of genome editing crops argue that if plants such as golden rice can be developed, it is unethical to deny millions of people a cure for diseases such as night blindness.
- Golden rice only focuses on one element of a poor diet. Programmes that improve access to vitamin-rich fruit and vegetables can be a more effective solution.
- In the UK, a recent trial was conducted using genome edited Camelina oilseed plants. These have been edited to produce omega 3 oil, potentially removing the need to feed small fish (the current source of omega 3) to farmed salmon. This could have animal welfare and environmental benefits.
- Some people argue that trying to solve global health problems through genome editing crops or fish isn't the answer. Instead, we need to move to more sustainable, varied and ethical farming and fishing models that use fewer resources that are more fairly distributed.
- According to the UN, the global population is expected to reach 10 billion by 2050. Genome edited food could help reduce the use of water, fertiliser and pesticides, and cut down food waste, while improving the amount of crops produced, diets and health.
- People who oppose genome edited foods worry that these crops could bring unintended and unknown long-term consequences to wildlife, ecosystems and human health.

ORANGE: FINAL QUESTION

Should scientists use genome editing to produce foods that can improve human health?

YELLOW: Climate friendly cows

Should genome editing be used to help solve environmental crises?

Climate change poses a threat to human and planetary life. As the Earth continues to warm, floods, fires and megastorms are becoming more common. Meanwhile, melting ice caps and glaciers will cause sea levels to rise, soaking large areas of fertile land with saltwater, eroding coastlines and flooding cities.

Farming plays a big role in climate change; farm animals produce around 14.5% of all greenhouse gas emissions. This is mostly from the methane in cows' burps. Methane is almost 30 times more powerful a greenhouse gas than carbon dioxide.

Scientists have found that there are microbes (tiny living things) in cows' guts that produce this methane - and there's a connection between these microbes and cows' genomes. Genome editing could be used to identify and treat the animals most likely to produce methane and reduce greenhouse gas emissions.

Consider this…

- For generations, cows have been selectively bred to produce the animals we're familiar with today that provide us with beef or milk. Genome editing to create cows that produce less greenhouse gas is simply a next step.
- There is an argument that keeping fewer cows in better conditions and reducing or giving up beef and milk are more ethical and sustainable solutions.
- There will always be people who want to eat meat and dairy products. Editing the genomes of cows, pigs, sheep and chickens to grow bigger, faster, and to provide more food for humans while reducing the impact on the environment should be a priority.
- Huge amounts of crops grown are used to feed animals. Animals are inefficient in turning these crops into proteins. Some people think that it would be more efficient to cut out eating meat altogether, freeing up farmland for other purposes.
- Genome editing could be used to improve the efficiency of how animals convert crops into protein. It could also be used to produce animals that are resistant to deadly viral diseases such as African swine fever or bird flu, which could become more common in a changing climate.

YELLOW: FINAL QUESTION

How do you feel about using genome editing tools to produce animals such as cows, pigs, sheep and chickens that could have a smaller environmental impact?

GREY: Sickle cell disease

Should genome editing be used to cure inherited diseases?

There are many diseases that can be inherited, such as sickle cell disease. Sickle cell disease means that red blood cells, which are usually round and flexible, are crescent or “sickle” shaped. These can clump together and clog blood vessels, which can cause severe pain, anaemia, stroke, organ failure and early death. Sickle cell disease can affect anyone, although it mainly affects people of African and Caribbean heritage.

Scientists have developed a number of ways to treat the disease using genome editing tools. In 2019, a patient in the US with sickle cell disease was successfully treated using genome editing. Firstly, special stem cells that can turn into different types of blood cells were removed from her bone marrow. The DNA of these stem cells was edited, so that they produced new, healthy red blood cells once they were put back into her bone marrow, replacing the “sickle” shaped cells.

Because this treatment is somatic, it only affects the individual rather than altering the DNA that is passed on to the next generation. That means the patient's children might still develop sickle cell disease, if they inherit the disease-causing gene variant from both parents.

Have a think about this…

- Somatic genome editing could be used to treat the estimated 15,000 people in the UK currently living with sickle cell disease. It could provide a one time treatment for sickle cell instead of a lifetime of medical interventions. This could hugely improve quality of life for those patients.
- The treatment is currently very expensive which means these treatments may not be accessible to the 200,000 to 300,000 children born with sickle cell disease in Africa each year.
- Sickle cell disease disproportionately impacts people of African and Caribbean heritage. Because of the legacies of slavery and the abuse of African Americans in medical research and experiments, as well as the ongoing racism and health inequalities that black people and people of colour face, many may be wary of potential new treatments like genome editing.
- Over 100 research projects and clinical trials are showing encouraging signs that genome editing could be used in the future to prevent or treat a wide variety of inherited diseases, including some eye diseases, HIV, haemophilia B (a blood clotting disease), cystic fibrosis (a condition that causes sticky mucus to build

up in the lungs and digestive system) and some cancers.

GREY: FINAL QUESTION

How do you feel about using genome editing tools to treat people with inherited diseases?

BLUE: Super humans

Should genome editing enhance our minds and bodies?

NASA, the US space agency, is currently working towards a future crewed mission to Mars. However, humans are not well suited to spending a long time in space. Exposure to radiation, the lack of gravity and years spent in an enclosed spacecraft would all have negative effects on the health of astronauts on a long space flight.

Scientists have identified more than 40 genes that could potentially be edited in the future to make humans resistant to radiation damage, grow harder and denser bones, be able to exist on less oxygen, be less anxious - and even smell less in confined spaces!

Talking points…

- Some people would argue that editing the human genome to produce people equipped for space travel is unethical. Other alternatives exist, such as robots and even artificial intelligence, which are much better suited to exploring new planets.
- It is unethical to edit future generations to be better suited to particular jobs, or to have other so-called ‘advantages’, as they have no control over that decision. Would you volunteer your own relatives?
- These futuristic enhancements may seem extreme now, but many of the ways that we try to improve our minds and bodies - from education and exercise to cosmetic surgery, or even access to new experiences and technology - would have seemed unbelievable to past generations.
- Closer to home, genome editing could be used to enhance our bodies to adapt to climate change - for example, needing less water or being able to withstand hotter temperatures.
- Genetic enhancements would be even more expensive than current lifestyle enhancements. This would increase inequality between those who could afford enhancement and those who couldn’t, creating a sense of ‘genetic advantage’ for a minority of people.

BLUE: FINAL QUESTION

How do you feel about using genome editing tools to enhance humans?

PURPLE: Malaria research

Should genome editing be used on entire species to get rid of infectious diseases?

Malaria is a disease caused by a parasite carried by infected mosquitoes, which pass on the disease through their bites. The parasite multiplies rapidly inside red blood cells before bursting out and infecting more blood cells.

According to the World Health Organisation, a child dies of malaria every two minutes and each year there are more than 200 million new cases of the disease. In 2020, an estimated 67% of all malaria deaths were of children under five.

Scientists at the Francis Crick Institute have been using the CRISPR genome editing tool to understand how the malaria parasite infects red blood cells. By editing the parasite's DNA to "switch off" an important section, they can see what happens when the parasite tries to multiply by breaking out of a red blood cell to infect others.

Consider this…

- Editing the genome of the malaria parasite in the lab to advance our understanding is part of basic scientific research. The experiment carries no risk of altering mosquitoes or the malaria parasite in the wild, and the results could save millions of lives by helping to develop new drugs specifically designed to target malaria.

- Beyond the lab, researchers are exploring using “gene drives” to reduce or even eliminate certain species of mosquitoes that carry the worst types of malaria. This uses special genome editing methods which make all the descendants of an edited male mosquito infertile. However, there are concerns that gene drives could have unintended negative effects on the ecosystems where these mosquitoes live.
- There are organisations in Africa and other Global South regions that voice concern that they may become test subjects for scientists from richer countries in the Global North. They see this as another kind of medical colonialism, where genome editing tools and their results benefit interests in the Global North, but may bring unintended consequences in communities where gene drives are carried out.

PURPLE: FINAL QUESTION

How do you feel about using genome editing tools to alter an entire species to save human lives?

GREEN: New frontiers:

Should we use heritable human genome editing for challenges that could be solved in other ways?

Heritable genome edits which are carried out on egg and sperm cells or early embryos, and which can be passed down from parent to child, present the biggest ethical

and safety concerns. In the UK it is only permitted in lab research to improve understanding of human biology and development, and is very strictly controlled. But using genome editing to alter the DNA of embryos for implantation in a person's womb is currently illegal in the UK and prohibited in many other countries. However, it is known to have happened once.

In 2018, Chinese scientist Dr He Jiankui revealed that his team had edited the genome of twin girls to try to prevent HIV transmission from their father, who carries the virus. The twins, and a third baby girl born soon after, are the first human subjects of heritable genome editing, meaning that the changes to their DNA could be passed down. Dr He was sent to prison for his unethical practice, and the experiment was widely condemned by the scientific community - particularly as there are other ways to avoid HIV transmission (and very effective treatments). However, Russian scientist Denis Rebrikov is one exception. In 2019 he developed a technique to edit a gene variant linked to deafness, and has said openly that he plans to implant genome-edited embryos for a number of D/deaf couples.

Talking points…

- Some people see heritable genome editing (if it can be shown to be safe, which it isn't at present) as one way to avoid passing on genetic conditions they view as severe.

- Many Deaf and disabled people are concerned that genetic conditions and difference are often seen as something to be avoided or ‘cured’. Heritable genome editing technology could be exploited to reinforce these beliefs, and be used in the future to erase aspects of disabled and Deaf people’s identities, when instead we should be challenging societal barriers to disability and negative attitudes to difference.
- In response to the He Jiankui case, the Chinese government reformed its laws and civil codes to create stricter regulations and governance of genome editing research.
- Regulating human genome editing globally is very challenging, and depends on a wide variety of processes, including control of research via funding decisions and peer pressure in the scientific community.
- Heritable genome editing would mean long-term monitoring of future generations of DNA-edited individuals in case medical problems appear down the line. Who would pick up the cost of dealing with those problems?

GREEN: FINAL QUESTION

How do you feel about using heritable genome editing, especially where there are other solutions ?

ZONE 4: MAKE YOUR MARK

Should genome editing be used in the fight against climate change? Should parents be able to alter the genomes of children yet to be born? Should genome editing be used to create new or ‘’improved” human abilities? How should these questions be decided?

From use in scientific research to combating environmental crises, from treating diseases to human enhancement, we want to hear your views about the ethics of genome editing. More people should have a chance to feed into how these technologies are used in the future, and this is a space for you to be part of these conversations.

So what do you think?

We invite you to write, draw, or record your reflections and questions on the ethics of genome editing, which will be shared with Crick scientists and staff. Jot them down on a tag or record them on the recorder.

Recorder Instructions: **Press button to start, Wait for the beep, Speak, Press button to finish**

Listen to comments left by others by picking up the audio handset and holding it to your ear, audio comments will play automatically. The handset includes an induction loop.

Post them to @TheCrick on Twitter or @thefranciscrickinstitute on Instagram with the hashtag #CutAndPaste.

Look out for answers to some of your questions from Crick scientists at crick.ac.uk/CutAndPasteAnswers. Some of your comments may also be explored at Crick public events that accompany the exhibition. For details, see crick.ac.uk/CutAndPasteEvents.

Please note that recorded comments & questions may be shared (in written form only) on the Crick website and social media. Written comments may also be shared online.

Glossary

Gene - A gene is the basic physical ‘unit’ of inheritance which is passed from parents to their biological children. The genes contain the information that shape a person’s physical and biological traits. Genes are contained within DNA.

DNA - Sequences of chemicals that are stored in thread-like strands called chromosomes which are found in the nucleus, the ‘control centre’ of the cell. Genes are written into DNA, which is inherited in every cell in the body.

Genome - The entire set of genetic instructions that are found in a cell. A genome is shared between all members of a species, but each individual has their own unique genome.

Genetic condition - A condition caused by a gene variant that is passed down from parent to child.

Pre-implantation genetic screening - A technique used to identify genetic variants in embryos that have been created through in vitro fertilisation (IVF).

Pre-natal testing - Tests that are performed on an embryo or a fetus, to identify whether (or the likelihood that) an embryo or fetus has a genetic variant.

Genome editing - A group of technologies that gives scientists the ability to alter an organism’s DNA.

Heritable genome edits - A form of genome editing, not currently legal in the UK and many other countries, that is carried out on the sperm or egg cells, or an early embryo, the effect of which is passed onto future generations.

Somatic genome edits - A form of genome editing that is carried out on an individual's body, the effect of which is not passed onto future generations.

Enhancement - In this exhibition, this refers to the concept of human 'enhancement' to achieve 'improved' physical or mental capabilities by means of genetic modification.

Genetically altered or modified organism - An organism, such as a plant, animal or human, whose genome has been altered by genome editing technologies.

Gene drive - A form of genome editing which provides a mechanism by which a desired genetic variant can be spread through a population (eg, in a species of mosquitoes)

Quotes scattered throughout exhibition:

“The human genome belongs to us all. It’s something we have in common, and so we all have the right to have a say.”

Françoise Baylis, Canadian bioethicist

“When it comes to genome editing, there needs to be a meeting in the middle of patients and experts. We need the clinical knowledge…but we should remember patients have the experience of living with conditions.”

Carole (UK), who lives with multiple rare and genetic conditions

(Quoted in Genetic Alliance UK’s 2016 report, “Genome editing technologies: the patient perspective”)

“Many of us see our disabilities as a rich and diverse culture, many of us want to pass that culture down to our children through our genes, and many of us see no reason not to.”

Rebecca Cokley, First Disability Rights Program Officer at the Ford Foundation, New York

“It’s wonderful. It’s the change I’ve been waiting on my whole life.”

Victoria Gray (US), the first patient to be treated for sickle cell disease using genome editing techniques.

“In the quest to eliminate suffering and pain, who has the power to decide which mutations warrant human gene editing while others are considered tolerable?”

Alice Wong, disabled activist, writer, editor and media maker based in California

“My hopes for genome editing are that the faulty gene can be removed from carriers so that they cannot have children who are affected, or who are carriers of the disease.”

Patricia (UK), whose grandchild lives with phenylketonuria (PKU), a rare and potentially serious genetic condition.

(Quoted in Genetic Alliance UK’s 2016 report, “Genome editing technologies: the patient perspective”)

“Technological inventions, like GM foods, are not going to solve the real social, economic, and environmental problems that cause hunger.”

Kumi Naidoo, Director of Greenpeace International

“Golden Rice is such an unnecessary technology. Resources used for its development should be channeled to the betterment of poor farmers who already produce these Vitamin A-rich food.”

Sylvia Mallari, global co-chairperson of People’s Coalition on Food Sovereignty

“We have a rising population – we are more than 100 million people and counting. If we do not adopt modern technology, many people will go hungry.”

Edwin Paraluman, farmer and Chair, Philippine Farmers’ Advisory Board

“Growing up, I understood that if you are farming and you are that vulnerable, there has to be something there to help, perhaps…disease-resistant animals...At the time, the science was not good enough to make a difference. And it was my commitment to change that.”

Professor Apollinaire Djikeng, Cameroonian biologist and director of the Centre for Tropical Livestock Genetics and Health, University of Edinburgh

“Ideally, we would reform farming practices, rather than modifying animals to fit them. But if we can’t achieve the ideal, the best option may be to pursue genome editing while also taking steps to reform factory farming.”

Katrien Devolder, the Oxford Uehiro Centre for Practical Ethics

“Would using genome editing technology to create the ‘perfect’ or ‘ideal’ human risk making us become less tolerant of ‘imperfections’? “

Corinne Othenin-Girard, PHD student in Sociology, Switzerland

“...some people won’t be able to resist the temptation to improve human characteristics, such as size of memory, resistance to disease and length of life. Once such superhumans appear, there are going to be major political problems with the unimproved humans, who won’t be able to compete.”

Stephen Hawking, Physicist, *Brief Answers to the Big Questions*

“We know our planet is warming, we know that our sun is going to die and this planet will be uninhabitable.If you believe as I do, that humans should go on, we need to find a way to make that possible.”

Jamie Metzl, technology futurist

“We really need something that gives us the oomph to remove this disease, especially in places in Africa that struggle with health systems. Even if there is some risk we should allow scientists to investigate them rather than say ‘don’t go there’.”

Fredros Okumu, director of science at the Ifakara Health Institute, Tanzania

“What happens if the gene drives are now mixed up with aquaculture? Does it kill the fish? Does it affect our ecosystems? …Mosquitoes play a very vital role in our ecosystems. The proposal to completely eradicate female anopheles mosquitoes will have severe effects to our ecosystems and our environment”

Barbara Ntambirweki, lawyer and activist, Uganda

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