Public dialogue on genome editing

Country synthesis report

By Ipsos MORI Social Research Institute for the ORION Open Science project

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Foreword

The advent of newer genome editing technologies that can make changes to the DNA sequence of an organism in a faster, more efficient, and more precise fashion has opened up a range of new possibilities, in research areas ranging from agriculture and food science, to basic bioscience and medicine. Ultimately, this technological progress has the potential to significantly improve human and animal health.

Realising this potential can only be achieved when scientific and technological developments evolve hand in hand with society. When one informs the other and *vice versa*. What benefits will the technology bring to citizens and under which circumstances do citizens accept those? As globalisation and digital platforms bring citizens closer together, and science increasingly becomes more open, do public attitudes differ across countries?

This synthesis report summarises the findings of an international dialogue conducted in the United Kingdom, Germany, Sweden and the Czech Republic. These national dialogues explored the views of the public to the use of genome editing in a research context and the potential future applications derived from it, the associated trade-offs and how research organisations should engage in the public discourse. This synthesis report highlights that public attitudes across countries remain fairly similar with regards to acceptability of genome editing uses and applications, with non-heritable genome editing for medical purposes the most acceptable possible future use, provided it was for tackling serious and severe life-threatening conditions and diseases. There were nuance differences in the trade-offs with Sweden, Germany and the Czech Republic valuing equality of access to the benefits of the technology over anything while in the UK the safety of possible applications was the prevailing compromise. Approaches to engaging citizens tended to prioritise wider reach methods over depth of knowledge exchange.

The findings of these dialogues are valuable evidence of the continued relevance of social justice as a prevailing value guiding scientific and technological development. With the forthcoming publication of the World Health Organisation Global Governance Framework, which includes ethical considerations and public engagement as key elements for its development, the findings of this dialogue are reassuring and make a timely contribution to ongoing discussions in this area in participating countries and globally.

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We would also like to thank all the stakeholders who participated in the stakeholder workshops and contributed to the development of the materials used in the public dialogues, as well as the experts who attended the public dialogue events and participated in discussions. The names of the stakeholders and experts who participated in the events in each country can be found in their respective country reports which are published alongside this overarching report.[3]

Most importantly, we would like to thank all of the members of the public who participated in the public dialogue events.

Members of the Advisory Group who have agreed to be named in this report are listed in Appendix E. The Babraham Institute's Public Engagement Team and the project team at Ipsos MORI who authored this report are listed in Appendix F. Members of the Review Groups and Ipsos teams in each country are listed within the respective country reports.

[1] https://www.orion-openscience.eu/about

[2] https://www.babraham.ac.uk/

[3] These reports can be accessed here: https://www.orion-openscience.eu/publications/report-and-papers

Executive Summary

The ORION consortium[4] commissioned Ipsos MORI to conduct a series of public dialogues focused on the views and concerns of the public regarding the application and implications of using genome editing[5] technology in ORION research institutions. Events were held in four countries where ORION partner institutions are located; the UK, Germany, Sweden and the Czech Republic. **This report synthesises findings from across the dialogues held in the four countries.** During the events, members of the public discussed applications of genome editing technology, possible future uses of the technology, and explored the best ways for the ORION partners to engage with the public about genome editing.

Views on key societal challenges and solutions

Societal **challenges identified across countries were interlinked**, including: economic inequality and poverty, climate change and food production, and physical and mental health including disease. Country specific concerns we also raised, such as access to healthcare in Germany. Participants across countries proposed similar solutions to these challenges. Although genome editing technology was not explicitly mentioned, solutions that genome editing has the potential to help realise were raised, including **scientific, technological, innovation and research-based advances**.

Knowledge and awareness of genome editing

While participants started the dialogue with a basic understanding of key biological concepts, in all countries, **knowledge of genome editing technology was low**. Participants found it easier to understand and relate to real world examples of how the technology could be applied. Across all countries some concerns related to the technology were raised at this stage, around ensuring how it will be used in **safe, ethical, and fair** ways.

Views of current and future uses of genome editing technology

Current basic research being carried out (even if it would not lead to real-world applications) was viewed positively and necessary for scientific developments in tackling disease and improving health. Some specific concerns were raised in each country about how genome editing technology was being used, relating to safety, ethics, equality of access and the impact on nature.

Several projective case studies were used to explore possible applications of the technology. **Across all countries acceptability of the potential applications of genome editing technology was linked to the direct benefits to humans and health.** For example, 'somatic genome editing'[6] was attractive to participants because of the potential of this application to **alleviate serious life-threatening diseases**. Conversely, applications that participants cautioned were those deemed risky to humans, such as heritable 'germline genome editing'[7], and

[4] ORION (Open Responsible research and Innovation to further Outstanding kNowledge) is a four-year (May 2017 - April 2021) project funded by the European Union's Horizon 2020 Research and Innovation Programme (agreement No. 741527) under the Science with and for Society (SWAFS) Work Programme, to build effective cooperation between science and various sectors of society.

[5] The advent of the CRISPR/Cas9 genome editing technique has made genome editing genome faster, more efficient, and more precise, and has instigated a range of new possibilities of the use of this technology, making public discussions about its use relevant and timely.

[6] 'Somatic genome editing' refers to edits in cells other than embryos, sperm and eggs, so that changes made to the genome are not heritable.

[7] 'Germline genome editing' refers to editing the genomes of embryos, sperm and eggs, so that changes made would be inherited by future offspring.

those viewed as being unnecessary, such as editing cosmetic traits in humans. Participants could see some benefit of genome editing crops and animals for food production and environmental purposes, but optimism was tempered by concerns around safety and impact of genome-edited organisms on ecosystems.

Communication and engagement

A discussion took place in each country about what scientific research institutions, like the ORION partners, should be saying to the public about genome editing technology, and what are the best methods of engagement. Participants across all countries felt it was important to be **transparent about what can and cannot be achieved using the technology to manage public expectations**. It is also important to communicate about **safety implications of the technology and how it is regulated, to provide reassurance that it is being used in ethical and fair ways**. There is a balance to strike between providing enough information to the public and not overwhelming them with technical detail. In Germany and the UK, participants said they wanted to understand **scientists' motives for using the technology**.

Across all countries it was felt to be important that ORION partners try to **engage as many people as possible** about genome editing technology given the potentially wide-reaching ramifications of its use, and participants suggested the best ways to do this would be using **online and video-based communication approaches**. At the same time, participants **valued opportunities for two-way engagement** where they could hear from experts.

An art piece was used within the dialogues to encourage participants to discuss a hypothetical scenario arising from genome editing technology and to facilitate discussions around ethical implications. The art **successfully provoked discussion** around these issues, particularly **where additional information was provided about it.**

Conclusions & recommendations

There were **some specific differences in public opinions between individual countries**[8], which are explored throughout this report, but overall, **there were overarching similarities in views across all four countries. These views form the basis of the conclusions and recommendations in this report**. Awareness of genome editing is low, so ORION should communicate transparently with the public about this technology including potential benefits and risks. ORION partners should be involved in supporting international regulations of the technology and this involvement should be visible to the public. Participants saw value in basic research, and it may be helpful for ORION partners to frame basic research as being exploratory, to help engage the public. There was fairly unanimous support for using somatic genome editing for medical purposes, so ORION partners could focus their future genome editing-based research on advancing this application area, while showing appreciation of ethical considerations of other applications. Participants thought online and video-based engagement methods would have the widest reach, so ORION partners should try to incorporate these methods into public engagement strategies, while simultaneously encouraging two-way methods of engagement where the public can hear from scientists directly. It may be possible for ORION partners to also incorporate art pieces into these strategies, but art should be shown alongside supplementary information to support people in understanding the artwork.

[8] These differences are summarised in Table 5.1: Table of key differences by country, in the Conclusions & Recommendations chapter of this report.

1 Background, objectives, and method

Background

1.1.1 About ORION

ORION (Open Responsible research and Innovation to further Outstanding kNowledge)[9] is a four-year (May 2017 – April 2021) project funded by the European Union's Horizon 2020 Research and Innovation Programme (agreement No. 741527) under the Science with and for Society (SwafS) Programme, to build effective cooperation between science and various sectors of society.

The mission of the ORION project is to explore ways in which Research Funding and Performing Organisations (RFPOs) in life sciences and biomedicine can open-up the way they fund, organise and perform research. The project aims to trigger evidence-based institutional, cultural and behavioural changes in RFPOs, targeting researchers, management staff and high-level leadership.

The vision of the ORION project is to "embed" Open Science and Responsible Research and Innovation (RRI) principles (ethics, gender, governance, open access, public engagement, and science education) in RFPOs, their policies, practices and processes.

The consortium of organisations participating in the ORION project is composed of:

Five Research Performing Organisations:

- The Babraham Institute (Cambridge, UK)
- Fundacio Centre de Regulacio Genomica (Barcelona, Spain)
- The Max Delbrück Center for Molecular Medicine in the Helmholtz Association (Berlin, Germany)
- The Central European Institute of Technology – Masaryk University (Brno, Czech Republic)
- The Centre for Research in Science and Mathematics – Universidad Autonoma de Barcelona (Barcelona, Spain)

Two research funders:

- Instituto de Salud Carlos III (Madrid, Spain)
- Jihomoravske Centrum pro Mezinarodni Mobilitu (Brno, Czech Republic)

Two research supporting organisations:

- Vetenskap & Allmänhet (Stockholm, Sweden)
- Fondazione ANT Italia onlus (Bologna, Italy)

[9] https://www.orion-openscience.eu/

1.1.2 About this public dialogue

In July 2019, the ORION consortium commissioned Ipsos MORI to conduct a series of public dialogues about the views and concerns of the public regarding the application and implications of the research performed by ORION institutions using genome editing technology. Four ORION partners participated in the project (throughout this section, the term 'project' is defined as the series of public dialogues in four countries), three of which are organisations performing life sciences research and one of which specialises in public engagement in science:

The Babraham Institute, Cambridge, UK - https://www.babraham.ac.uk/

Publicly-funded, world-class research institution, undertaking innovative biomedical research in over 20 research laboratories that collectively focus on understanding biological mechanisms underpinning health and wellbeing throughout the lifespan.

Max Delbrück Center for Molecular Medicine in the Helmholtz Association (MDC), Berlin, Germany - https://www.mdc-berlin.de/

One of the world's leading research institutes in life sciences and member of the Helmholtz Association of German Research Centres, Germany's largest scientific organisation. MDC conducts basic biomedical research to understand the causes of diseases at the molecular level with the mission to translate discoveries as quickly as possible into practical applications, aiming to improve disease prevention, diagnosis and therapy.

The Central European Institute of Technology (CEITEC), Brno, Czech Republic - https://www.ceitec.eu/

Established in 2009 as an independent institute focused solely on research, since 2011 it operates as a consortium consisting of four leading Brno universities and two research institutes that joined forces to establish a superregional centre of scientific excellence combining life sciences, advanced materials and nanotechnologies.

Vetenskap & Allmänhet (Public & Science; VA), Stockholm, Sweden - https://v-a.se/english-portal/

Non-profit association established in 2002 with the purpose of promoting dialogue and openness between researchers and the public. VA has around 90 member organisations representing research organisations, public authorities, institutes and universities as well as companies and private associations. VA acts as a knowledge hub for public engagement and science communication in Sweden, disseminating knowledge and experience, gained by itself and others, and developing toolkits and best practice guidelines.

This report synthesises findings from across the dialogues held in the four countries. There are also individual country reports available, these report on findings from each country separately.[10]

[10] These reports can be accessed here: https://www.orion-openscience.eu/publications/report-and-papers

Aims and Objectives

Genome editing technology is a broad term describing a collection of methods that enable changes to be made in DNA - the genetic material of all cells. Whilst genome editing techniques have been available for many years, the advent of the CRISPR/Cas9 genome editing technique has made targeted editing of the genome faster, more efficient, and more precise. This has opened up a range of new possibilities, in research areas ranging from agriculture and food science, to basic bioscience and medicine. The genome editing technique CRISPR/Cas9 provides a good model of a recent disruptive biotechnology. Disruptive technologies are those that have the potential to impact society, are able to displace an established technology, shake up an area of research, or create a completely new area of research.

The aim of ORION's public dialogues was to explore public views regarding the research that ORION partners conduct using genome editing technology and possible future potential applications of this technology and to gather evidence on when and how research-performing organisations should engage with society about disruptive technologies.

Specifically, the dialogue sought the following objectives:

- How do the public trade-off the benefits and dis-benefits and potential unintended consequences arising from genome editing?
- Under what conditions are the public willing to make these trade-offs? For example, in what contexts and for what purposes?
- To understand the boundaries of acceptability of the technology, as well as what reassurances the public needs in order to support the use of the technology.
- What are the public's hopes and fears regarding the ORION partner's research using genome editing?
- What mechanisms should ORION partner organisations use to be open about their research and at what stage in the process should the organisations engage with the public?
- To understand how public engagement strategies might differ between countries within the ORION partnership.

Participating ORION organisations sought to increase two-way engagement with the public in order to make better decisions informed by a wide range of views and values, about how and when to engage with the public on disruptive technologies; and to develop mechanisms that provide links for public and stakeholder engagement back into its research and impacts. Findings from this dialogue are also intended to be transferrable to other areas of disruptive science and technology outside of genome editing.

Method

The dialogue within each country had important input from the ORION participating organisations and their national stakeholders. These groups provided input into the materials in order to ensure they reflect the genome editing research carried out by the participating research organisation and the national context of the use and regulation of genome editing within each country. In addition, scientists and other technical experts from participating organisations and their networks joined in the dialogue events to provide specific knowledge and expertise.

The dialogue method used in each country is outlined in each of the individual country reports. A consistent approach was followed across the four countries to support analysis of the entire dataset, leading to the production of this final synthesis report that summarises the main conclusions and similarities and differences across countries.

1.1.3 Public Dialogue workflow

All stages of the public dialogues were carried out in the UK initially, followed by the other three countries, which replicated the approach taken in the UK. The events took place in the UK first because the UK ORION partner, the Babraham Institute, led the project. The decision to run the events firstly in the UK was made in the context of the UK having a long-standing tradition of public engagement in science.

Overall, the project proceeded in the following stages:

1. The ORION consortium commissioned Ipsos MORI to run a project consisting on a series of public dialogues in four European countries and developed the project specification.

2. Ipsos MORI worked with the Babraham Institute, the ORION partner leading the project, to develop the materials to use at a stakeholder workshop.

3. A workshop was held with key stakeholders in each country, with expertise in genome editing, policy, ethics, law, and science communication and engagement. The purpose of this stakeholder workshop was to provide a diversity of insight into the framing and scoping of the materials to be shown during the public dialogue events. The date and location of the stakeholder workshop in each country is outlined in the table below.

4. Findings from the stakeholder workshops were used to help develop materials for the public dialogues. Each institution provided three to four examples of their research using genome editing to present to the public in the form of case studies.

5. The research materials[11] used in the public dialogue events were initially reviewed by the Babraham Institute and adaptations were made by Ipsos MORI. The Advisory Group[12] commented on a revised set

[11] Research materials – these were the materials used in the public dialogue events. This included the discussion guides used by moderators in the events, the plenary presentation slide deck shown to the public, and case study handouts for participants providing examples of how genome editing techniques are currently used by researchers in each country.

[12] An international Advisory Group was convened to provide oversight and governance of the overall project (the term 'project' is defined as the series of public dialogues in four countries). The Advisory Group membership consisted of international stakeholders with knowledge and expertise in genome editing, the ethical issues associated with the technology, and science communication as well as senior management from each of the four ORION partners involved in the project.

of materials and further changes were made. A Review Group[13] within each country then further reviewed the materials before they were finalised. A list of members of these groups can be found in the appendices of the individual country reports.

6. A pair of public dialogue events within each of the four countries were held with roughly 30 members of the public (one on a weekday evening and the other on a Saturday 1-2 weeks later). A staggered approach was taken, with events first being carried out in the UK, followed by Germany, Czech Republic then Sweden. The dates and locations of the events in each country are outlined in the table below. Experts attended each of these events, their role was to ensure that the genome editing technology and related ethical and societal issues were presented in an accurate and balanced way, and to answer questions that the participants had about these issues.

7. Findings from these events were written up into four country-level reports, and this overarching synthesis report pulling together findings from across the countries.

Table 1.1: Table of public dialogue events by country

	Stakeholder workshop	Event 1	Event 2
UK	10th September 2019	24th October 2019	2nd November 2019
Germany	23rd September 2019	6th November 2019	16th November 2019
Czech Republic	18th September 2019	21st November 2019	30th November 2019
Sweden	2nd October 2019	23rd January 2020	8th February 2020

1.1.4 Public dialogue events

In order to recruit participants to the public dialogue events, Ipsos MORI developed recruitment materials to be used by each country's recruiters. These recruitment materials consisted of a set of documents which provided information about the research to potential participants, incorporated a screening questionnaire which collected information about participant characteristics, and had space to record contact details if participants confirmed they were available and interested to participate in the research.

[13] A Review Group was set up within each country to help framing the public dialogue materials to reflect the national and institutional context.

The screening questionnaire asked about demographic factors including participants' gender, age, ethnicity, parental status, employment status, sociodemographic segment and where participants lived. Quotas were set on these variables to reflect the national population and ensure diversity in the participants attending the events, with recruitment of particular groups of participants stopping once that quota had been achieved. Participants were also asked about their awareness of and attitudes to genome editing technology and quotas were set on this.

The approach taken by the recruiters in each country differs slightly and specific details of each country's recruitment process can be found in the individual country reports, as well as further details about the structure of the public dialogue events.

The two events of the reconvened public dialogue events served different purposes:

Event 1 (3-hour evening workshop): The focus of this event was to give participants the minimum amount of information needed to engage in discussions about the use of genome editing technology and the issues arising from it. Participants were informed about key biological concepts including DNA, gene, genome, and proteins, this enabling them to discuss different research uses of genome editing technology. Once participants had learnt about these biological concepts, they were shown and discussed case studies based on their country institution's research using genome editing.

Event 2 (day long Saturday workshop): During this event, case studies outlining their country institution's research were re-introduced to remind the participants about the type of research currently conducted in their country, and this was followed by a discussion of possible future uses of the technology. The afternoon involved discussion of how best to communicate and engage the public around genome editing technology. Part of this conversation involved capturing participants views on an artwork that was specially commissioned for the dialogue, which depicted a possible far off future where genome editing technology has enabled the slowing down of the ageing process.

2 Views on key societal challenges and solutions, and knowledge and awareness of genome editing

At the start of the first dialogue event in each country, participants were invited to think about key challenges and problems facing society, how they imagine those challenges could be solved, and what role technology could play. This allowed people to feel comfortable talking about issues and also revealed if their stated societal challenges overlapped with the benefits that can potentially be realised by genome editing. Participants' knowledge and awareness of genome editing was also gauged.

Many societal challenges identified across countries were similar and often also interlinked

Similar societal challenges were raised across the four countries. These fell into three main themes:

1. economic inequality and poverty;
2. overpopulation, climate change and food production; and,
3. challenges related to physical and mental health, including disease.

The challenges raised were often interlinked. For instance, challenges around resource inequality (access to medicines/healthcare and resources such as food not being shared fairly) were discussed in the context of a growing world population. Environmental concerns such as climate change and plastic in our oceans were linked with issues of sustainable food production.

"Climate change we've also got. Famine and lack of water resources. As a way to try and reduce famine, [there needs to be] at least improved food production throughout the world."
Event 1, Cambridge, UK

Some country-specific challenges were also raised. These were:

- Brexit, the rise of populism and identity politics were mentioned as challenges facing society in the UK.
- In Germany, access to healthcare within a system of public/private health insurance was raised as a concern, and related to this, the power of pharmaceutical companies was concerning for participants. The unknown impact of genetically modified crops and perceived lack of regulation of this were also concerns.
- In the Czech Republic, participants mentioned poor quality foods replacing natural ingredients. They also spoke of concerns relating to globalisation in terms of the power of global corporations and non-democratic states.

- In Sweden, participants were concerned about the spread and control of global pandemics. Participants were also concerned about digital security – how secure their personal data was, and who is able to access this.

Participants across countries offered similar solutions to these, including political and economic solutions as well as scientific, technological, innovation and research-related solutions

Solutions offered by participants to these key challenges tended to fall into two categories which were consistent in each of the four countries.

1. Political and economic solutions: in relation to funding resources and research which could address the challenges discussed above and the sharing of resources more equitably to address economic inequality. In Germany, the Czech Republic and Sweden, the importance of improving education was discussed at this stage of the dialogue.

"There needs to be more money. So, resource to tackle disease."
Event 1, Cambridge, UK

2. Scientific, technological, innovation and research-related solutions: in relation to tackling food and health challenges, for instance, developing technologies to make crops more durable, and using science and technology in healthcare to improve diagnoses and prevent diseases. This second category contains solutions that genome editing technology could potentially deliver.

"Global food sufficiency cannot be solved with the use of convention tools. Science must step in."
Event 1, Prague, Czech Republic

The solutions proposed by participants in each of the countries fell into the two broad categories outlined above, but participants in each country considered different specific examples and solutions. These related back to ways to solve the key challenges that they had previously discussed:

- In the UK, participants suggested the use of laboratory grown meat products could help to tackle climate change by reducing the need for farmland and reducing greenhouse gas emissions. They also suggested access to healthcare could be improved using video conferencing technology or other innovative communication methods.

- In Germany, participants thought that technology could be used to optimise treatments or assist in early diagnosis (using technology to speed up diagnosis was also mentioned in the UK).

- In the Czech Republic, participants mentioned global sharing of information and joint scientific practices as potential general solutions to the challenges they raised.

- In Sweden there was an emphasis on the need to fund research to combat all the challenges raised.

While participants started the dialogue with a basic understanding of key biological concepts, in all countries the general knowledge of genome editing technology was low

Across all countries there was a basic understanding of key biological concepts, but participants were mostly unaware of genome editing technology. Only a few participants within each country knew about it from the start.

As soon as they learnt about genome editing technology, participants were looking for what the real-world benefits of the technology could be, such as medical advances. Participants recognised that genome editing had the potential to be a powerful technology and were interested in the opportunities it presented.

"Cool. I am excited that we are so far that we can cut out specific things out of the genes and replace it with something else. These are incredible opportunities."
Event 1, Berlin, Germany

"I see endless opportunities. It is positive for treating diseases, growing resilient plants, not even so much water will be needed."
Event 1, Prague, Czech Republic

Some concerns around safety, ethics and fairness of the technology were also raised at this stage across the countries. Details of the differences by country around this are outlined below:

- When participants in the UK were first introduced to genome editing technology, they expressed concern that not everyone in the scientific community would use genome editing techniques responsibly. Trust in scientists and the need for global regulation of the technology was discussed at this stage.

- Participants in Germany firstly associated genome editing technology with the potential to bring benefits in medicine. However, they also had concerns relating to fairness and access to the technology at this stage – that possibly only the wealthy will be able to use it – and related this back to the public/private healthcare divide in the country. Ethical concerns were also raised at this point over using the technology for non-medicinal purposes.

- When Czech participants learned about genome editing technology, they discussed the potential for it being used in agriculture and the food industry, as well as for medical purposes. Czech participants also raised concerns around fairness and safety; they were concerned about the technology being used by special interest groups to push ideologies such as for religious interest, as well as in the interest of non-democratic countries (relating back to the initial challenges about this that Czech participants had raised as facing society).

- In Sweden specifically, participants discussed a need to improve knowledge among the public, including making it clear to people what the distinction is between genome editing and genetic modification, as there was some initial confusion around this (this confusion also came up in the UK dialogue but was raised further along in the discussions). This discussion was reflective of the broader discussion in Sweden on the important role of education in engaging the wider public with genome editing research.

Limitations of current genome editing techniques were also discussed in Sweden at this stage, with help from the experts present.

3 Views of genome editing techniques (current and future)

Basic research was positively received and viewed as necessary for scientific developments in tackling disease and improving health

Participants within each country were shown three to four different case studies of basic research using genome editing techniques currently carried out by the ORION partnership organisation that operates within their country.[14] It was explained to participants that this work being conducted by the ORION partners was typically fundamental biological research ('basic research') aiming at understanding biological processes underpinning living organisms, which may or may not eventually lead to practical applications. The full case study handouts shown to participants in each country can be found in Appendix A.

Participants across the four countries were not initially aware of what basic research was, but they were positive about this research being carried out even if it would not lead to real-world applications in the end. This is because they saw basic research as necessary for scientific development. When they were discussing genome editing generally, participants tended to look to the potential practical, real-world applications of genome editing and discussed whether these were of value (and hence related more to case studies where they could see these practical applications more easily). For instance, research for medical purposes or that would tackle disease was viewed as most valuable and having the most potential; people were excited by the opportunities in this area.

"People suffer. It is a good idea to cure disease, but who has access to it [this technology]?"
Event 1, Stockholm, Sweden

"It's the first step of a long process. Hopefully at the end, it eradicates diseases whatever it may be."
Event 1, Cambridge, UK

"There are many things in the world that can be abused. As long as it can save lives, I'd go for it!"
Event 1, Prague, Czech Republic

Across the countries, there was support for clear regulation on the uses of the technology on an international scale, and to avoid the risk that the use of the technology being misused and abused.

"It [genome editing] might be regulated in this country but not in others."
Event 1, Cambridge, UK

[14] Each case study was presented as a one-page handout. In Sweden, where the ORION partner organisation does not conduct research using genome editing techniques, participants were shown case study examples based on the work of other Swedish scientists.

There were, however, some concerns relating to safety, ethics, equality of access and the impact on nature

Participants across countries discussed similar benefits that could be achieved from the technology. The differences between countries tended to relate to the concerns raised around the technology at this stage. These fell into overall themes of safety, ethics, equality of access and the impact on nature, as discussed below:

- In the UK, some case studies were presented where the practical applications of the technology were less clear and participants struggled to understand these and had a lot of questions around how these techniques are used and how they work. Participants felt it was important that a lot of in-depth research using genome editing technology was carried out before it is used in an applied way, with safety fears at the heart of this. There was surprise about the progress that had already been made with the technology and participants were encouraged to know it was being used widely in UK laboratories.

- In Germany, there was also surprise about the progress that had already been made. Concerns raised were with the technology leading to interference in natural eco-systems, causing unintended effects. There was also concern around the influence those who fund the research have on the research process (this concern was also raised in the Swedish events), and how can it be ensured that there is access for all to the benefits of the technology, not just a select few.

- In the Czech Republic, support for basic research was strong and trial and error was seen as a part of the research process even if it does not lead to applied outcomes. In contrast to the concerns raised by German and Swedish participants, Czech participants felt comfortable with the technology only initially benefitting a few people in society, as they felt it would become more accessible to others over time. However, there was some worry about misuse of the technology by those that have access to it and worsening existing inequalities in society.

- In Sweden, as in Germany, concerns were around who is funding the research and the impact this has on the research process. Participants also felt it is important to consider whether the expense of research is always worth it and what is the best use of money. They argued that research into diseases is important but there needs to be prioritisation – the deadlier a disease, the higher priority it should be. They had specific concerns that only wealthy countries would have access to this technology and about potential issues with ensuring personal data protection.

In the Czech Republic and Sweden, participants were also presented with case study examples of research on crops and plants using genome editing techniques. There was some enthusiasm for this research in the Czech Republic, while in Sweden participants were more neutral towards their case study (using genome editing techniques to produce low glycemic index potatoes) and had concerns about potential knock-on effects in nature.

"What happens to the farmers and what are the consequences in nature?"
Event 1, Stockholm, Sweden

There were some indicative differences in views by demographic groups, typically by age and gender, with younger participants and men finding the technology more appealing

As the dialogue events were carried out with small groups of people in each country, these are only indicative findings of differences between different groups of participants.

- Among UK participants, males under 35 tended to be more positive and accepting of the use of genome editing technology, and women less so. Those who were older (of either gender) tended to have more worries about it.

> ***"The knowledge is already there; the practice is already there. Going back to the ethical question if one feels one can't control it how can it ever stop now it has started? Why weren't these questions asked before they started trying to develop it?"***
> *Event 1, Cambridge, UK*

- In Germany, participants with higher levels of educational attainment appeared to have a higher awareness of ethical debate and understanding of genome editing. There were differences by gender as men focussed on genome editing as a technological advancement, while women tended to focus on the potential to improve quality of life through genome editing. Like in the UK, older participants tended to have more concerns about the possible unintended drawbacks of the technology.

- Similarly to Germany, in the Czech Republic those from a higher educational background were better able to understand the risks of using genome editing technology and women tended to focus on the potential health benefits. At the same time, men found the technology appealing because of its low cost and therefore accessibility.

> ***"It is humane. Children who will never be functional, all around suffer with it…It would be beneficial to mankind."***
> *Event 1, Prague, Czech Republic*

- In contrast, in Sweden, there were no notable differences in views by demographic groups. Views stemmed from where the conversation began instead. For example, in a group where economic issues were raised early on within the discussions this became a more prominent theme within this group.

> ***"Most research is funded privately and it's hard to know what their vested interests might be."***
> ***Event 1, Stockholm, Sweden***

Somatic genome editing for medical purposes was the most acceptable possible future use of the technology given the potential of this application for tackling serious and severe life-threatening conditions and diseases

Participants were shown a range of future possible uses of genome editing applications, designed to enable them to reach some conclusions around what constitutes acceptable and less acceptable usage (these can be found in Appendix B).

Non-heritable genome editing for medical purposes ('somatic genome editing')

In all countries, 'somatic genome editing'[15] for medical purposes was attractive to participants because of the potential of this application for **tackling serious and severe life-threatening conditions and diseases**. However, there were also nuances between countries:

- In the UK and in Sweden, participants discussed the use of the technology for non-life-threatening conditions and diseases (like deafness, blindness, Down's Syndrome and Autism). The use of the technology for these purposes was **less acceptable** given the perceived lesser severity of these conditions and (in some cases) the removal of choice for individuals. In these countries, discussions around the uncertainties in curing the disease, and in Sweden the uncertainties in passing on the edited genes to offspring, limited the acceptability for this application of the technology.
- In Germany, while somatic genome editing was initially viewed less efficient than germline genome editing[16] (where changes can be passed on to offspring), as participants discussed this further, they were comforted that the **results will be confined to those who have chosen to have their genome-edited**, thus any unknown effects will not passed on.
- In the Czech Republic and in the UK, the chance that **there could be inequality in access**, with only the wealthiest being able to afford it, hampered enthusiasm among some.

Genome editing plants and crops

There were varying levels of appeal to the application of genome editing in plants and crops across countries, and participants within each country saw some benefits of this:

- In the UK and in Sweden, participants became drawn to the potential of this application in **tackling food insecurity and shortages and solving hunger and food affordability.** In Sweden, participants were also drawn to the idea of editing crops to make them **more nutritious.**
- In Germany, the potential for this application in the context of **climate change** was the factor that made this application of genome editing more acceptable.
- In the Czech Republic, participants did see some value in using the technology on crops in order to make them **more resilient to the environment** to survive increasing droughts caused by climate change.

However, concerns were also expressed in each country about this application of genome editing technology:

- In the UK and in Germany, there were questions over the **unknown effects on humans of consuming genome-edited plants**, and the **unknowns surrounding the introduction of edited plants into the natural ecosystem**. In the UK, some participants automatically associated genome-edited crops with genetically modified crops, which caused some uncertainty.

[15] 'Somatic genome editing' refers to edits in cells other than embryos, sperm and eggs, so that changes made to the genome are not heritable.
[16] 'Germline genome editing' refers to editing the genomes of embryos, sperm and eggs, so that changes made would be inherited by future offspring.

- In Germany participants initially **struggled to see the use of this application of genome editing technology**, as food was already considered accessible and affordable.

- In the Czech Republic, this application of the technology was **not considered to be as important as other uses such as those that would tackle disease** – with participants unable to justify the apparent need for the use of this application of the technology and instead offering alternative suggestions (e.g. those allergic to gluten can solve this with their diet, rather than modifying wheat to be gluten-free).

- In Sweden, the focus of concerns was around the safety of the technology and specific concerns were raised about **transparency in research and in food labelling**. In Sweden, participants said that they needed to know more about what happened to their food so that they could judge for themselves whether it was safe to eat.

Genome editing animals and livestock

In all countries except Germany, participants recognised some of the potential advantages of **editing the genome of animals and livestock**:

- In the UK and in Sweden, participants recognised the potential benefits around using genome editing to **treat disease and genetic conditions in animals,** which would make them healthier. In the UK, additionally, participants liked the idea of genome editing assisting more environmentally friendly farming.

- In the UK and Czech Republic, participants viewed the transplantation of animal organs to humans (known as xenotransplantation) as **acceptable if it was proven to be safe**, because of the potential life-saving potential for humans. Participants in Sweden also saw the benefit of this but were concerned that there are still too many unknowns to ensure it was safe. In Germany, participants initially found the idea off-putting but eventually came around to accepting it as it could help to support human life.

- In the UK and Sweden, participants could see **possible medical benefits of genome editing insects** such as editing the ability of mosquitoes to carry malaria.

For several reasons, the concerns and unknowns around genome editing animals and livestock tended to outweigh any benefits, and this reasoning differed slightly between countries:

- In the UK and Sweden, and in Germany (where the application was highly controversial), there were concerns about the **unknown effects on humans of consuming genome-edited animals**. Participants in the UK and in Germany were also concerned over **animal welfare**, if genome editing animals meant they would be treated poorly.

- In the UK and in the Czech Republic, concerns too were raised around the creation of genome-edited livestock **interfering with the natural eco-system**.

- In the Czech Republic, participants were concerned about genome editing insects **interfering with natural ecosystems and disturbing the food chain.** In Sweden, while participants could see potential benefits to genome editing insects, they also felt that there were **too many unknowns currently** to ensure this would be safe.

Heritable genome editing for medical purposes ('germline genome editing')

Across the four countries, there were a mix of quite negative reactions to 'germline genome editing' for medical purposes, though with some subtle country differences explaining the reasoning for this:

- In Sweden, the UK and in the Czech Republic, the risks associated with the potential **unknown repercussions for many generations of people** was a concern for many. Because of this, in the UK and in the Czech Republic this was the most controversial potential use of the technology. However, in both countries, participants were more accepting of the (future) potential for this application of the technology to be used to treat serious and devasting diseases, for example Huntingdon's disease.

- In Sweden, the concerns about germline genome editing focused around the **creation of a supposedly 'superior race'** of people with superior genes in comparison to everyone else.

- In Germany, initially the potential to eradicate diseases using genome editing technology was viewed with great optimism and participants preferred the use of germline genome editing for this purpose over using somatic genome editing, because they felt that germline genome editing would be more efficient in achieving changes (as changes would be passed on to offspring). As with the UK and the Czech Republic, by the end of the discussion, and after recognising the drawbacks, **it was clear to participants that for now, heritable germline editing should only be used to cure or prevent inheritable illness where this was would result in relieving people from suffering.**

Genome editing to change or enhance human traits

Universally, across all countries, the use of genome editing technology to enhance or change traits in humans (such as changing eye or hair colour, or increasing endurance) was viewed **negatively and as unnecessary and unnatural.** Across countries, very few benefits were identified. Participants had various objections:

- In the UK, in Sweden and in Germany, participants were strongly against this application of genome editing technology and cautioned the risk of **exacerbating divisions** in society and **creating inequalities** between those who will be able to afford editing their traits and those who will not.

- Additionally, in Germany, there was caution over a society where **everyone will be physically similar**, and one that strives to create a superior race.

- In the Czech Republic this application reduced participants' initial enthusiasm for fast application of genome editing technology being used in practice.

- In Sweden some discussions went as far as to suggest an outright ban of this application of genome editing technology.

4 Communication and engagement

A key research objective for this project was to better understand how the ORION partners should engage with the public about disruptive technologies like genome editing. In the second public dialogue event within each country, a discussion took place about this – what messages should scientific research institutions be communicating to the public about genome editing technology, and how should they be saying these?

As part of the discussion around how and what is the most effective way to communicate the issues arising from genome editing technology, participants were shown the exhibition 'ÆON - TRAJECTORIES OF LONGEVITY AND CRISPR'[17] created for the purpose of these public dialogues, in collaboration with artist Emilia Tikka and one of the ORION partner organisations (MDC, Germany), and were asked to reflect on it.

ORION partners should be engaging with the public transparently around safety and regulation of the technology, and realistic benefits/risks, to manage public expectations

Across all four countries, participants thought that transparency from scientists about genome editing technology was key. Having learnt about the technology at the events, it was clear to participants how powerful genome editing technology had the potential to be. They viewed it has having major potential benefits but also major potential risks. Therefore, it was viewed as important for scientists to communicate with the public about these risks and benefits, this included levels of safety of the use of the technology in different contexts. Participants welcomed to be regarded as stakeholder and to be included in the discussions by ORION partners, particularly where research could lead to applied uses of genome editing technology that would affect their lives.

"I think it's great that you see us as the stakeholder. We're the end users. I haven't experienced the scientific community thinking that way."
Event 2, Stockholm, Sweden

One way to help to achieve this transparency is for scientists to communicate about both their successes and their failures (or if not 'failures' as such, whether the research has found what they were anticipating and why). Participants thought that by doing this, scientists would be able to manage the expectations of the public in terms of what is realistically achievable using genome editing technology, or if that is unknown, what is likely or unlikely to be achievable.

- In the UK participants thought there would be value in scientists communicating where they had not succeeded or where there were difficulties in using the technology.
- In Germany participants suggested scientists should communicate about both the potential positive and negative implications from using the technology.

[17] https://www.emiliatikka.com/new-page-1

- In the Czech dialogue workshops, participants were particularly keen for scientists to communicate about their successes using the technology and the potential benefits of it, using applied examples where possible. In this country discussions focused more on potential benefits than risks.

- In Sweden on the other hand, much of the discussion focused around potential risks of using genome editing technology. To this end, ORION partners should try and communicate risk to the general public, including how new research findings affect how risky or safe a procedure is.

"[Scientists need] To show what benefit it brings in the countries where it is permitted."
Event 2, Prague, Czech Republic

"It is important to show up and down sides. Do not sugar-coat it. People should be able to form their own opinion."
Event 2, Berlin, Germany

There was recognition across the countries that the impacts of genome editing technology would not be geographically limited to one nation or continent and that European science organisations like the partners in ORION should collaborate in the development of regulation on the use of the technology and in how it is communicated to the public. The example discussed of the Chinese scientist He Jiankui illegally genetically engineering human twins emphasised this need for international agreement on how the technology will be used.[18]

"It [genome editing] might be regulated in this country but not in others."
Event 1, Cambridge, UK

- A key finding from the UK public dialogue was the need for there to be some form of internationally agreed and respected public-facing documentation which outlines the current state and possible future applications arising from the use of genome editing technology. This should inform the reader that genome editing techniques, despite being in their infancy regarding their use in applied clinical settings, could bring wide-ranging benefits which cannot yet be predicted with certainty. The public should also be informed about what the current regulations are around genome editing technology – what is and is not currently accepted / legal? This documentation would help to answer some of the questions and issues raised through this dialogue around whether the technology is being used in safe, ethical, and fair ways. Participants felt that as scientists working for ORION partner organisations are experts in the use of genome editing, they are well-placed to play an important role in the development of such documentation – perhaps by working with other scientific organisations or advising policymakers and government in order to do so.

- In Germany, participants felt that highlighting the regulatory European framework within which MDC (the ORION partner in Germany) operates could help to build public confidence.

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[18] https://www.theguardian.com/world/2019/dec/30/gene-editing-chinese-scientist-he-jiankui-jailed-three-years

"The information we've been given in this is pretty good. I don't think that's difficult information to get out there to people. What the possibilities are. What the reasons for it are. What the possible outcomes are. Who would have access to it?"
Event 2, Cambridge, UK

In Sweden and the UK, there was some confusion over the difference between the terms 'genome editing' and 'genetically modified', typically when participants were discussing the use of the technology on crops. However, once it was explained to participants that genetic modification involved introducing foreign genetic material from another organism while genome editing involved editing genes that already exist in an organism, they quickly understood this distinction. In their public-facing outputs, ORION partners should make clear to the public what the difference between these two is. This will help to address fears about the use of the technology.

"I thought I had been against GM foods. It has made me think differently about the possibilities now…I thought with foods and messing about with stuff is not good. Now I can see there is a lot of potential for better things."
Event 2, Cambridge, UK

There is a balance for the ORION partners to strike between providing enough detail about genome editing techniques, and not confusing the public with too much technical information, which could discourage people from engaging with the work scientists are doing.

- Participants in the UK and Czech Republic countries were particularly interested in understanding potential real-world applications of the technology and advised not to go into too much detail about how the technology works as people might lose interest if they cannot understand it.

- In Germany, participants felt that genome editing techniques are complex and could be intimidating for people to understand. It was not always immediately clear to participants why different applications and areas of research using genome editing (such as for medical purposes, on livestock, on plants) were important, so it is worth ORION partners clearly explaining why research is being conducted in these different areas.

- In contrast, in Sweden, participants were keener than in the other countries to understand details of the research processes and not just the end results or applications. They were also interested in understanding who was funding the research. It was felt they needed this nuanced information to be able to develop informed opinions about how genome editing is used.

Overall the ORION partners need to try to strike this balance by communicating about the research they are doing using genome editing technology and the outcomes they hope to achieve, but at least at first not going into too much technical detail. It may be a good idea for the ORION partners to position their work as exploring how life fundamentally works as this could help to pique the interest of members of the public – this was a finding from the UK events. The technical details of research could still be accessible via academic journal articles or similar, but ORION partners must acknowledge that much of the public would not be interested in seeking out this information. If members of the public were interested in further detail, the ORION partners could signpost them to where they can find this information.

"I imagine the technicalities of it in terms of the specifics are probably not so necessary. Unless you're going to try it yourself, you don't need to know."
Event 2, Cambridge, UK

Another finding across the countries was the desire for better education and information to be presented using clear and accessible language, written in public-facing layman's terms. For example, in practice this could mean substituting terms like 'somatic' and 'germline' for 'non-heritable' and 'heritable' in communications.

"The most important information is surely education, because I think that the population knows too little. When I as an "amateur" know more, I can ask more detailed questions."
Event 2, Berlin, Germany

It was clear from the dialogue events in Germany and the UK that it is not only important for scientists to communicate about genome editing technology itself, but it is just as important for scientists to communicate about their underlying values and motivations for using the technology. This could help to build trust between the public and scientists, and people may become more open to learning about scientists' research using genome editing technology. Findings from the dialogue events show some particularly good potential ways for scientists to be able to do this, which are explored further in the next section:

- Show scientists speaking directly to the public about their own work (and provide them with the tools and resource to be able to do this).
- Have a two-way communication strategy between the public and scientists – being able to ask questions and receive responses was highly valued by participants in the dialogue events.

"It is important to know their values because this builds trust. To create trust is important, more so than turning people into experts."
Event 2, Berlin, Germany

Participants wanted engagement methods about the technology to reach as many people as possible, therefore they suggested using online and televised approaches

Across the four countries, participants enjoyed participating in the public dialogue events, because it gave them the opportunity to talk to scientists, and have their opinions heard and questions answered. They greatly valued this two-way method of engagement. However, across all of the countries participants also recognised that this method has limitations in the number of people it could reach.

"I think this is a more valuable experience for us and for your guys as well. It is a complex topic and we have broad spectrum of people some with no scientific background you need to be educated about it and then talk about the ethical thing. It is quite valuable to do it in this way."
Event 2, Cambridge, UK

"By being able to engage, you can get more information. You also have the feeling that you are a part of it."
Event 2, Berlin, Germany

Across all the countries, participants saw the need for ORION partners to communicate with as many people as possible about genome editing technology. This was because the technology was considered to have potentially big impacts on society. Most participants at the beginning of the events did not know about the technology or its associated ethical issues in any of the countries, and it is likely that the public at large across these countries do not either.

- For this reason, participants in Germany and the UK thought that children should be taught about it in school. The ORION partners such as the Babraham Institute in the UK already do educational outreach work within schools and in light of this it may be beneficial to increase this work further if possible.

"I would have put education in schools at the top."
Event 2, Cambridge, UK

- Having learnt about genome editing technology and its associated ethical implications, participants in Sweden expressed surprise that they had not seen these issues being discussed through popular media channels.

During the second event within each of the countries, participants were shown examples of methods of communication and engagement between scientists and the public.[19] Because of the prevailing view that as many people as possible should learn about genome editing technology, in each country participants felt that multiple methods of communication should be harnessed by the ORION partners.

"It needs to be more than one type of media. There is no ideal communication platform, where you can reach everyone."
Event 2, Berlin, Germany

- In the UK, a 'building-block' approach to engagement was suggested where engagement methods with a wide reach are initially used to pique people's interest, who may then seek out more in-depth information about the technology in other ways.

- A similar approach was suggested in Germany, where it was suggested the MDC website could be a foundation for a communications strategy and provide links to a range of communication channels.

There was a particularly strong preference in all four countries for two methods of communicating with the public that have a wide reach: TV and social media. The ORION partners should be maximising the use of their

[19] Methods discussed were as follows: animated videos, videos of scientists talking about their work, television, academic journals, the Babraham Institute, CEITEC, MDC and VA websites, social media, Citizen science, citizen forums, printed media, Public Science festivals, exhibitions showing the technology and open days and theatrical performances.

existing social media platforms and if possible, develop a strategy for televising their research. It was felt that these two methods in particular would enable the ORION partners to reach the most people.

"All the social media platforms have their pros and cons. Twitter is more about written communication, Instagram works a lot via hashtags. Facebook is a mixture. But generally it is a lot about visual content."
Event 2, Berlin, Germany

- In the Czech Republic, it was felt that of these two suggested approaches, the use of social media would be more appealing to younger members of the public and televised approaches may appeal more to older audiences. In Germany, participants also considered TV to be more popular among older groups.

In terms of content, videos of scientists talking about their work were rated highly by participants. It may be possible for ORION partners to film and publish videos of scientists on their websites, or perhaps there are opportunities to have scientists representing these organisations participate in broader documentaries about genome editing technology. Having scientists talking directly about their work makes it more transparent and accessible and could help to build trust with the public.

- In the UK, participants thought this information would be better coming directly from scientists rather than a PR figure or a celebrity. At the same time, there was some concern in the UK dialogue not to over-burden scientists if they are required to perform public engagement activities.

- The exception to the above point is if information comes from a well-known and trusted figure who is also an expert in that field; this was a suggestion from a Swedish participant. In Sweden it was suggested that scientists may need training on how to engage effectively with the public, as this is likely not their area of expertise. It may be possible to train members of staff within each ORION partner institute to act as ambassadors for their institute and act as a point of contact for the public regarding genome editing research.

"Your knowledge [the experts] makes it comfortable for us. I think that is incredibly powerful. If a polished celebrity was to talk, then it wouldn't come across as well."
Event 2, Cambridge, UK

"You would almost need a cult figure or advocate, along the lines of Hans Rosling, who knows what life is all about. Not a purchased PR person."
Event 2, Stockholm, Sweden

Animated videos were also rated highly by participants across all the countries, as they were viewed as being highly accessible and able to communicate information quickly – which was viewed as a benefit when communicating about a technology as complex as genome editing. However there was also recognition that it is difficult to convey lots of complex information about the technology or its associated ethical issues in a short, animated video. Participants in each country were shown an animated video from the Royal Society during the dialogue events.[20] The perceived downside of this type of video content is that it does not allow for a two-way conversation between the public and scientists in the same way that the public dialogue events did. Another perceived downside of creating video content is that it could be potentially expensive and time-consuming to create.

"I'd definitely click on some interesting video sent to me. Those spread among people awfully fast."
Event 2, Prague, Czech Republic

- YouTube is a widely used public platform, and some participants in the German events mentioned that they had used popular YouTube channels to learn about science. It may be possible for the ORION partners to use their own YouTube channels, or link in with other popular scientific YouTube channels, to engage the public about their research.

- In the Czech Republic, while animated videos were liked by participants, some felt they could be child-focused and overly simplistic.

- Participants in the Swedish events perhaps criticised the animated video they were shown for being too positive about genome editing technology and not nuanced enough. For this reason, they felt animated videos could be too simple to the point of being unbalanced.

The ORION partners should at first communicate the types of information requested by the participants in these dialogue events through communication channels that the public most widely use. In addition to TV and social media, advertisements in public spaces, and events about science open to the public were viewed as valuable starting points across the countries. In each country, participants saw value in other methods of engagement as well and weighed up the pros and cons of each. For example, a traditional method of communicating scientific findings, via academic journals, was viewed as valuable to the scientific community but not accessible to the public. Below are some country-specific views and suggestions about methods of public engagement:

- In the UK, there was a suggestion that scientists could place photos of themselves and their contact details on any online articles they had written about genome editing. This would help to build trust and enable the two-way method of engagement participants valued at the public dialogue events.

- Open Days and Citizen science piqued an interest in participants at the German events because they presented opportunities for increased engagement with scientists. The perceived limitation of these types of methods was that they tend to be used by people who already have some interest and knowledge in the subject matter.

- Participants in the Czech Republic suggested various novel methods for educating the public about genome editing, including; showing videos about genome editing technology in the waiting rooms of

[20] https://www.youtube.com/watch?v=XPDb8tqgfjY

healthcare providers or on public transport; incorporating it into TV shows such as quizzes or dramas; developing board games based around genome editing; and reading about it in news or lifestyle magazines.

- In Sweden, participants were particularly critical of using printed media to engage with the public about genome editing technology, as it was viewed as being outdated and obsolete. Whereas in the other three countries, participants could still see some benefits to using printed media as a method of communication, even if they considered it old-fashioned (as was mentioned in the UK) or on the decline (as mentioned in the Czech Republic).

The art piece was successful at provoking discussion around the issues arising from a potential future use of genome editing technology, but was more successful in doing this when additional information was provided about it

The ORION consortium wanted to incorporate a piece of art into this public dialogue as a different mean of encouraging participants to discuss a potential future scenario arising from genome editing technology and to facilitate discussions around ethical implications of the technology. Accordingly, the ORION project launched a competition for commissioning this art piece in May 2018, which was managed by ORION partners in Berlin, the Max Delbrück Center for Molecular Medicine (MDC). Emilia Tikka, an artist, designer and PhD candidate at Aalto University, The School of Arts, Design and Architecture in Helsinki, won the bid with her work entitled '*Trajectories of longevity and CRISPR*' (*AEON*)[21]. For this art piece, Emilia designed a speculative scenario of a rejuvenation technology embodied as a device for daily use and narrated as a fictional photographic story. Participants within each country were shown and/or told information about the artwork.

[21] https://www.emiliatikka.com/new-page-1

Figure 4.1: Images of AEON Trajectories of longevity and CRISPR

Due to practical constraints, while the artwork was used in the public dialogue events within each of the four countries, it was presented in different ways, as follows:

- UK – the artwork was physically present during the second event.
- Germany – the artwork was physically present during the second event.
- Czech Republic – it was not possible to show the physical artwork, so during the second event images of the artwork on Emilia Tikka's website were shown to participants, alongside a video of Emilia talking about the piece.
- Sweden – the artist, Emilia, was able to attend the first event and give a brief introduction to the artwork in person. Then, the artwork was physically present for the second event and was re-introduced to participants. Prior to the events participants were invited to attend the unveiling of the artwork at the venue.

An aim of the art piece was to provoke discussion around the issues arising from a potential future use of genome editing technology. It successfully stimulated discussion about genome editing technology, sparked debate, and elicited an emotional response from participants. There were differences in how participants reacted to the art piece by country:

- In the UK, it was successful, to an extent, at provoking discussion as participants were able to talk about their reflections on the art. Participants reported it making them feel less optimistic about the technology than they had previously been, but they were also aware their views were being influenced by the choices of the artist such as the use of black and dark colours in the piece. They felt that if the artist had chosen to use bright colours or images of people smiling, it would completely change how it made them feel about the technology. Some participants in the UK were confused by the piece and mistook it to be a piece attempting to promote genome editing technology, albeit unsuccessfully.

  "It is subject to the artist's interpretation and then your interpretation about his [sic] depiction."
  Event 2, Cambridge, UK

  "For me this is just a viewpoint but it's also a red line. It's about age. It wouldn't be something that I would be promoting."
  Event 2, Cambridge, UK

- The art piece successfully provoked debate in Germany and raised many questions among participants. It led participants to choose sides: would they have been an opponent or proponent of using the technology in this way? It made participants who were previously positive about the technology uncomfortable. Like in the UK, German participants recognised the piece reflected the artist's interpretation but there was also a perception that portraying the technology in a more positive light would not have provoked discussion or led to more nuanced views.

"From our reaction you can see that it provokes people to think. Through art you have the opportunity that people engage with a topic. Everyone can take from it, what they want."
Event 2, Berlin, Germany

- The art piece successfully provoked a heated discussion and emotional responses in the Czech Republic. The majority of participants rejected the idea of using genome editing technology to prolong ageing as they thought this could cause societal problems, especially if some people in society age at a normal rate while others do not age.

"This would raise so many ethical issues. This won't affect just the individual involved but their whole community."
Event 2, Prague, Czech Republic

- In Sweden, the art piece was very successful at stimulating discussion and drawing out emotional responses from participants. Even when participants stated that it was not helpful in stimulating discussion, this very statement ironically led to a discussion around genome editing. Some participants felt the art piece was boring and said they would have preferred an interactive piece or something that provided backstory. Participants in Sweden recognised that different people like to take in information in different ways, so art pieces like this can be useful ways to engage the public. At the same time, they felt it is difficult for a piece of art like this to convey lots of information about a specific topic in a clear and balanced way.

The artwork seemed to stimulate more discussion where there was more information provided about it, such as in the Czech Republic where participants saw a video of the artist talking about the work and the piece inspired heated debate, and in Sweden where the artist spoke to participants about the art piece. Without the additional information it could be more confusing or unclear for people what it was depicting (such as in the UK where some mistook it for a promotional piece). Therefore, this engagement method benefits from explanatory, supplementary information being presented alongside the art itself.

Across the countries, participants liked the concept of using art like this piece to communicate issues as it made them think and feel differently about the issues they had been discussing. In the UK and Czech Republic there were also concerns that this medium would only particular segments of society; many people do not visit art galleries, so would not experience this type of art.

"A very particular type of person goes to an exhibition. I don't know if it would effectively communicate to everybody."
Event 2, Cambridge, UK

A suggestion from the Swedish participants was to display this artwork in several different prominent public spaces in order to maximise its audience. Participants across different countries felt that genome editing technology and the ethical issues around its use should be taught to children in schools; this type of artwork could be an effective way of teaching and engaging young people in a school setting.

"Bring out the exhibition that so that people actually see it. You should be able to take it round libraries and cultural centers."
Event 2, Stockholm, Sweden

Overall, art work can be effective at stimulating discussion and communicating ethical issues however it should be presented alongside other information about genome editing. Doing this would maximise the audiences' understanding of the topic enabling participants to develop more informed views.

5 Conclusions & Recommendations

In this chapter, we firstly summarise the key differences in findings between countries that have been discussed in detail throughout this report. Then, we outline our overall conclusions and recommendations drawn from similarities across the countries.

The table below summarises country-specific differences for the themes covered in each chapter of this report, namely:

- views of the key challenges facing society, solutions to these and participants' starting points about genome editing;
- views of genome editing techniques (current and future); and,
- views of communication and engagement about genome editing.

These three sections are colour coded in the table below for clarity, with each colour representing a different section.

Table 5.1: Table of key differences by country

Theme:	Country:	Key differences:
Views of the key challenges facing society, solutions to these, and participants' starting points around genome editing	UK	Challenges mentioned specifically in this country: A unique challenge raised in the UK was Brexit and the rise of populism/identity politics. Solutions mentioned specifically in this country: To tackle climate change, a specific solution suggested was lab-grown meat. Improved access to healthcare via technology. Participants' starting points around genome editing: Initial concern that scientists may not use the technology responsibly.
	Germany	Challenges mentioned specifically in this country: Access to healthcare within a system of public/private health insurance, and the power of pharmaceutical companies. Unknown impact and perceived lack of regulation of genetically modified crops. Solutions mentioned specifically in this country: Technology to assist in early diagnosis and optimising treatments. Participants' starting points around genome editing: Initial optimism about medical benefits but concern that only the wealthy will be able to access it and around it being used for non-medical purposes.
	Czech Republic	Challenges mentioned specifically in this country: Poor quality foods and the replacement of natural ingredients. Globalisation, the power of global corporations and non-democratic states. Solutions mentioned specifically in this country: Global sharing of information and joint scientific practices was seen as a general solution. Participants' starting points around genome editing: Initial thoughts that it could be used it agriculture, but concerns about it being exploited by special-interest groups or non-democratic states.
	Sweden	Challenges mentioned specifically in this country: The spread and control of pandemics. Digital security of personal data. Solutions mentioned specifically in this country: A need to fund research was seen as a general solution. Participants' starting points around genome editing: Initial views that there needs to be improved education among the public r.e. genome editing technology (and its distinction to genetic modification), and a discussion around the current technical limitations of the technology.

Views of genome editing techniques (current and future)	UK	**Current uses:** Participants struggled to understand the case studies presented and the link to practical applications. Sentiment that a lot more research needs to be performed before this technology can be used in an applied way, and it is reassuring that these techniques are being widely used in UK laboratories. **Future uses:** Participants discussed various benefits and concerns of each of the potential future applications presented to them, but these were not UK specific and were also raised in the other countries.
	Germany	**Current uses:** Participants expressed surprise that the technology was already this advanced, and concerns raised about interference with ecosystems, the influence of research funders, and ensuring equal access to the applications of the technology. **Future uses:** Germline genome editing for medical purposes initially viewed as more efficient than somatic genome editing, but after a discussion of the consequences of germline genome editing, participants felt the latter is currently more applicable, as it was seen as more controllable – unintended effects will be limited in being passed on.
	Czech Republic	**Current uses:** Particularly strong support for basic research and the research process, even where this does not lead to applied outcomes. Participants were more comfortable with the technology benefiting only a minority at first, assuming that its applications are eventually more accessible to a wider group. Concern was expressed however around misuse of the technology exacerbating inequalities. Some enthusiasm for the case study about applying genome editing to plants. **Future uses:** There was positivity about genome-edited crops being resilient to droughts caused by climate change, but this was not seen as important as medical applications for the technology. Participants disliked the idea of genome editing technology being used to enhance traits in humans and this reduced participants' previous general enthusiasm about the technology.
	Sweden	**Current uses:** Concern around who funds research and whether or not it is always a good use of money. There was also concern that only wealthy countries would have access to the technology and around potential issues with protecting individuals' data. Neutral about their case study applying genome editing to plants due to concerns of knock-on impacts on nature. **Future uses:** There were concerns about the uncertainties of somatic genome editing for medical purposes, around whether the genetic changes definitely would not be passed on. Participants liked the idea of genome editing being used to make crops more nutritious but had concerns over the safety of eating genome-edited crops and how these foods would be labelled. There were serious concerns around germline genome editing and editing human traits, with some participants suggesting this should be banned outright.

Views on communication and engagement	UK	**What should organisations like the ORION partners be saying about genome editing:** Participants thought there was value in scientists communicating where they had not succeeded or where there were difficulties in using the technology. A key finding from the UK public dialogue was the need for there to be some form of internationally agreed and respected public-facing documentation which outlines the current state and possible future applications arising from the use of genome editing technology (referred to as a 'roadmap' in the UK country report). **What methods of engagement should organisations like ORION use:** A 'building-block' approach to engagement was suggested where engagement methods with a wide reach are initially used to pique people's interest, who may then seek out more in-depth information about the technology in other ways. Participants felt information should come directly from scientists rather than a PR spokesperson or celebrity, and at the same time there were concerns that scientists could be overburdened with requirements to engage with the public. There was a suggestion that scientists could place photos of themselves and their contact details on online articles they had written to encourage two-way engagement. **Views of the art piece:** The art made participants feel negatively about the technology, but they acknowledged this was related to the artist's interpretation. Some participants were confused by the art and mistook it as a promotional piece for the technology.
	Germany	**What should organisations like the ORION partners be saying about genome editing:** Participants suggested that scientists communicate about both the potential positive and negative implications of genome editing technology, and clearly explain why conducting research about different applications of the technology (e.g. medical applications, using plants, with animals) is important. They also felt it was important to highlight the European regulatory framework that their ORION partner organisation operates within. **What methods of engagement should organisations like ORION use:** Participants suggested the ORION partner website could act as a foundation for other engagement methods. Open Days and Citizen science piqued interest in participants at the German events because they presented opportunities for two-way engagement. **Views of the art piece:** Participants in Germany chose sides, whether they would be an opponent or proponent of the technology being used in this way. Participants felt that if the art had been presented in a more positive way, it might not have led to a nuanced discussion.

	Czech Republic	What should organisations like the ORION partners be saying about genome editing: Participants thought that scientists should focus on outlining the current and potential benefits of the technology, using real-world applications where possible. What methods of engagement should organisations like ORION use: Participants felt that TV would appeal more to older groups and social media to younger groups to communicate about genome editing. They suggested various novel methods of engagement about genome editing, e.g. incorporating it into TV quizzes or dramas and developing board games based around genome editing. Views of the art piece: The piece led to heated discussion, though some participants were unsure of the relationship between the two characters depicted.
	Sweden	What should organisations like the ORION partners be saying about genome editing: Much of the discussion in Sweden focused around potential risks associated with genome editing technology. Unlike the other countries, participants in Sweden were more interested in understanding details about the research process and not just the end results or applications. What methods of engagement should organisations like ORION use: Participants were surprised they had not heard about genome editing/ethical issues related to the technology through popular media channels and suggested these should be used to reach the public. A finding from Sweden is that scientists may need training to engage with the public. Swedish participants were particularly critical of printed media as an engagement method. Views of the art piece: Even where participants felt the art did not help to provoke discussion, this ironically led to a discussion about the issues depicted. Some participants would have preferred an interactive piece with more backstory provided. There were suggestions for artwork like this to be displayed prominently in public spaces.

While there were some differences in the findings by country, as outlined in the table above and throughout this report, overall many of the findings were reported across countries. The table below outlines our conclusions drawn from the public dialogue events across all four countries and makes recommendations for the ORION partners based on these conclusions. These are based on similarities in the findings across countries. Specific conclusions and recommendations for each country can be found in the individual country reports.

Table 5.2: Table of overall conclusions & recommendations across countries

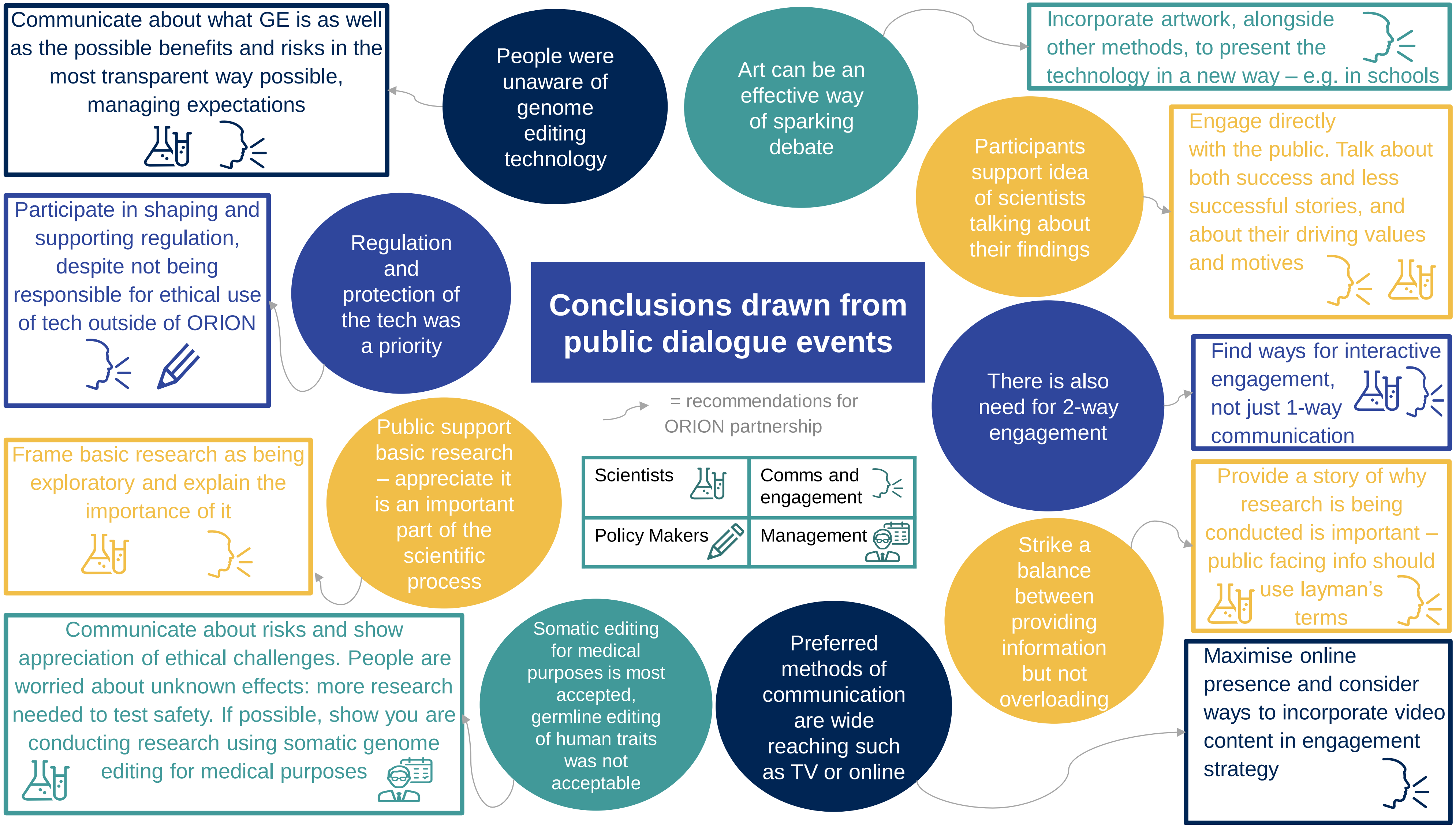
Conclusions	Recommendations	Recommendation for:
Participants were unaware of genome editing technology.	Communicate with the public about what genome editing is and how it can be used, including both the possible benefits and possible risks. This should be done in an authentic and honest way that explains where the technology is at now whilst managing expectations of what the future could bring.	• Scientists – the public trust scientists, so they will be important for raising awareness of the technology • Communication and engagement specialists – need to effectively communicate with public about the technology
Once people understood the technology, they were very keen for there to be protections in place and strict regulation to prevent misuse. ORION partner organisations should actively support a fair and safe use of the technology. The public did not necessarily see it as the ORION partnership's responsibility to ensure the technology was used ethically outside of the partner organisations but more that they should be actively supportive of the idea of fair, safe use.	Participate in shaping the regulations of genome editing, for example by advising policy makers. ORION partners should promote and assist the development of internationally agreed documentation that states what is and is not allowed regarding genome editing technology. The public and advocacy groups may also need to be involved in the development of this.	• Communication and engagement specialists – should communicate about the ORION partners' stance on ethical use of the technology • Policy makers should reach out to ORION organisations' scientists for guiding use of the technology and to outline ethical regulations

Participants did support life sciences and biomedicine fundamental basic research, even if it does not necessarily lead to applied outcomes. They saw this as an important part of the scientific process.	Frame research as being exploratory, highlighting the importance of developing a learning of how biological processes work in order to increase our understanding about life. This will help the public to understand the value of basic research.	• Scientists – explain rationale and moral behind their basic research to gain further public's support; it is important to community 'why' research is being conducted as well as 'how' • Communication and engagement specialists – provide the tools and support needed for scientists to be able to communicate about their research effectively
Participants were most accepting of the use of somatic editing for medical purposes when considering future possibilities of genome editing. Participants found somatic genome editing most acceptable when it was to tackle serious or life-threatening disease, and only if it has been proven to be safe. They saw potential value in genome editing crops and animals, but this was less of a priority than medical applications of the technology. Their biggest worry was the use of germline editing and editing human traits due to the possible ethical implications on society and unknown/unintentional consequences.	Communicate safety/risk implications of research to the public. Further research needs to be conducted using genome editing technology before it can be used in applied settings to ensure it is safe. Demonstrate you are conducting research using somatic editing for medical purposes if possible, as this area of research was most valued by participants across the four countries. Show appreciation of ethical challenges surrounding germline editing and object to attempts to use the technology to enhance human traits.	• Scientists – it is important for them to know what the public think is acceptable using genome editing technology and what isn't acceptable • Management within ORION partners – should guide the type of research being conducted in the institutions to ensure it remains ethical and in-line with the public's priorities

When it comes to communicating with the public about genome editing technology, participants felt that as many people should learn about it as possible due to its potential impacts. Participants therefore valued methods of communication they were already using (TV, online) as these have the widest reach.	Maximise ORION's online presence such as its social media channels and use accessible videos where possible, as this strategy could have the widest reach. Also explore the possibility of televising research and findings. If this is not feasible due to resource implications, it may be possible instead to link in with existing documentaries or popular science channels either online or on TV.	• Communication and engagement specialists – it is important to know, and use, the best ways to engage public
There needs to be a balance between providing enough information whilst not overwhelming people with too much technical detail, which could cause them to disengage.	Provide a story of why research is being carried out, what it hopes to achieve and the value it hopes to bring, as it is important for the public to understand the motivation and values behind scientists' work. Ensure that public-facing information uses layman's terminology, for example using terms like 'heritable' as opposed to 'somatic', so that the research is accessible for as many people as possible.	• Communication and engagement specialists – need to effectively communicate with public about the technology • Scientists – when presenting their research or findings to the public, scientists should try to minimise jargon and complexity
Participants seemed to enjoy participating in the dialogue events as they were able to interact directly with experts and hear responses to their questions.	Find opportunities for a two-way method of engagement between the public and scientists, alongside methods of communication such as online videos or social media. This could involve running open-days or other events where members of the public can meet scientists, or online interaction such as including the contact details of scientists at the top of articles they publish about their research.	• Communication and engagement specialists – try and use methods of engagement with the public that allow for a discourse between scientists and the public • Scientists – be open to interacting with the public about the research

Participants supported the idea of scientists talking about their own work as it aids transparency.	Engage with the public about the work of scientists. Scientists should be able to talk to the public directly about their own work and about both when their research has been successful and less successful (or, where it has met or not met their expectations). Hearing this from scientists directly rather than a celebrity or PR professional increases public trust.	• Scientists – scientists are deemed as trustworthy; the public will take more note if information comes from them. Communicate about values and motivations behind the research • Communication and engagement specialists – should make use of scientists when considering communication methods, as this could increase trustworthiness of communication • Management within ORION partners – engaging with the public may be outside of scientists' expertise. There should be training to explain how to do this, and how to do it in a way which does not overburden scientists.
The art piece was an effective way of sparking debate or getting people to think about issues in a different way. It was successful in this case where lots of additional information was presented alongside it. Participants thought that this mode of engagement will not appeal to all parts of society.	Incorporate artwork into engagement methods when communicating about genome editing technology, but if used, this should be alongside other engagement methods to ensure the technology is presented in a balanced way. Artwork could be used for example in schools and education as way to engage children.	• Communication and engagement specialists – different methods of communication will be more/less effective for different parts of society, so a mix of different methods should be used

Figure 5.2: Diagram of conclusions & recommendations



Appendix A: Case studies shown to participants

UK case studies:

Editing model organisms

Babraham scientists discovered an important biological "switch" in the 1980s.

This switch is made from the 'PI3K' family of proteins. These proteins control how cells grow, how cells reproduce, what jobs are done by cells, and even how long cells live for. These are important factors for our health and maintaining our health as we age.

Using GE techniques, scientists are also looking to identify more proteins that help control this switch.

If scientists found a new protein involved, they could use genome editing to edit its DNA in mice so that it no longer worked.

By looking at the effect this has on mice they could learn the role this new protein plays in controlling the PI3K switch.

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Epigenetic marks

Scientists now know that the way our genes work can be affected by factors in the environment such as chemical 'marks' that get stuck onto DNA throughout our lives – as well as the DNA sequence itself. These 'epigenetic' marks help determine which parts of the DNA code can be read.

BI scientists study how epigenetic marks in a mother's egg cells can affect how the DNA is used in her children's cells.

Using GE techniques, they hope to be able to understand how changes such as the mother's age and diet can affect the epigenetic marks, and if these changes can be passed on to offspring.

If scientists found epigenetic marks that controlled a gene involved in disease, they could use CRISPR to edit the epigenome and change these marks. They could switch off genes that cause disease, or switch on genes that prevent disease. These changes could potentially be passed on to offspring.

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How the immune system works

The cells of our immune system produce antibodies to defend us from bacteria and viruses.

As we age, the number of different antibodies we can produce starts to decrease, and our immune system stops working as effectively.

Using CRISPR/Cas9 BI scientists study what causes our immune system to decline as we age: why do we produce fewer antibodies; why does our immune system not respond as well as when we are young, and why do vaccines not work as well?

If scientists found that they could use CRISPR to edit the human genome and reverse this age related decline, then they could improve the immune systems of older people and stop them from getting so many diseases.

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Germany case studies:

Converting skin cells into egg cells

The northern white rhino is as good as extinct, as the species only has two remaining females, and they are directly (genetically) related.

As numbers declined, researchers began collecting and deep-freezing tissue samples (skin cells), and (sperm cells) from northern white rhinos.

Turning a piece of skin into a living rhinoceros would be a truly remarkable feat of cell engineering – one that still requires a great deal of research.

MDC has achieved the first step, using tissue taken from a different rhino species, to convert skin cells into stem cells.

The next steps for MDC have never been done with the rhino species: stem cells ➔ germ cells ➔ egg cells.

This process has been done before in mice, although it took many, many years.

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How does titin affect heart growth

Scientists edited the titin gene in mice in different ways and looked at the effect this had on the mice.

They found that one change in titin caused the mice to have bigger hearts, and a different change in the same gene caused the mice to have smaller hearts.

The scientists hope that in future, knowing which changes cause which effects will help doctors diagnose people better, and could lead to personalised treatments for patients.

Once we understand what changes cause what effects, a possible treatment could involve using genome editing to correct these specific changes.

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Understanding gene expression

One sign of kidney disease is 'albuminuria'. This is when proteins leak out of your kidneys into your urine.

Scientist know that there is an area of the genome associated with albuminuria. This area contains many different genes and MDC researchers wanted to find out which one is responsible for causing the disease.

Using rats and zebrafish scientists found one gene that was important. When they turned off the gene, using CRISPR, the zebrafish leaked a florescent green molecule out of their kidneys, showing that this gene was the cause of the leaky kidneys.

Working with other scientists, they showed that this same gene is changed in some human patients.

Now scientists know that the same thing happens in humans and zebrafish, they can use zebrafish to understand how turning off this gene causes leaky kidneys.

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Editing model organisms

Brain tumours like glioblastoma multiforme (GBM) are one of the most aggressive forms of cancer, and very difficult to treat.

MDC researchers are using CRISPR-Cas9 to re-create human cancers in mice in the hope of finding new medical therapies. They insert tumour cells into mice and let them grow.

The mice are then humanely killed and researchers are able to look at the cells in the tumour, and how the cancer has responded to a certain therapy.

They are looking at how the tumour cells have grown and whether the cancer cells develop resistance to certain therapies.

By doing this they hope to understand how and why some cancers stop responding to chemotherapy, and find new ways of testing whether human patients will respond to a specific type of chemotherapy.

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Czech Republic case studies:

Re-programming immune system cells

Cancers are caused by 'glitches' in a cell's DNA that change the genetic instructions that allow us to grow and develop healthily.

There is always more than one DNA glitch needed to cause cancer. The combination of different glitches varies between patients – each cancer is unique.

CEITEC researchers are trying to develop a new treatment for cancers such as leukaemias and lymphomas, called CAR-T therapy.

Healthy immune system cells are taken from a patient's blood. They are edited using CRISPR to recognise the specific combination of changes in that patient's cancer.

The cells are then put back into the patient in order to target that patient's cancer.

This research involves the use of mice that have purposely been given cancer.

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15

Understanding how plant molecules work

The two molecules that scientists use most often to edit the genome are <u>CRISPR</u> and <u>Cas9</u>.

These molecules occur naturally in plants and are used by the plants' immune systems to stop them getting diseases.

Scientists can put these molecules into other types of cells (humans, animals, other plants) and use them as a tool to edit the genome. They act like a pair of molecular scissors!

Plant scientists at CEITEC study how CRISPR and molecules similar to Cas9 are involved in plant's immune systems.

They look very closely at the molecules and try to understand how they work.

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Understanding how viruses work

Bacteria are tiny living organisms that can survive on their own or inside a host such as a human. They can be harmful or helpful to other organisms.

Viruses are also tiny living organisms, even smaller than bacteria that can only survive by invading the cells of a host.

Some viruses don't infect humans, animals or plants, but can actually infect bacteria, and can harm or even kill bacteria!

Scientists at CEITEC are studying how these bacteria-infecting viruses work, and how they invade bacteria cells.

One day, scientists could potentially use genome editing to alter the genomes of these bacteria-infecting viruses.

They could programme them to kill bacteria that are dangerous to humans, or kill bacteria that have developed antibiotic resistance.

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Swedish case studies:

Genome edited potatoes

Plants, including potatoes have traditionally been genetically modified by selective breeding to give desired traits both in terms of taste and crop yield.

Genome editing provides a faster way to edit crops to study them or improve them by making them more nutritious or resistant to pests and extreme weather.

Scientists have successfully tried CRISPR on potatoes after previous technologies introduced too many genetic errors.

Genome editing has now been successfully implemented in potatoes, producing new starch qualities for improved usability in food, such as a low-GI potato i.e. a potato with reduced sugar content.

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Genome editing bacteria to produce biofuels

Genome editing can be used to produce biofuels. A biofuel is made from biomass, i.e. plant or algae material or animal waste.

Plants and some bacteria can produce sugars from light and carbon dioxide using a process called photosynthesis.

These sugars can be processed to produce biofuels, but **what if** the processing wasn't necessary?

Scientists are working on genetically modifying bacteria to directly produce biofuels from only light and carbon dioxide.

This research aims to contribute to the future of fuel production.

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2

Editing embryonic stem cells

Age-macular degeneration is the leading cause of severe, permanent vision loss in people over age 60. It happens when the small central portion of the eye's retina, called the macula, wears down.

A treatment for this disease could be to use embryonic stem cells to replace the damaged cells in the eye. These cells are taken from **undeveloped** human embryos, mostly from IVF treatments, and they have the ability to become any type of cell in the body.

Because the cells come from a donor, the patients immune system would normally reject these cells.

Scientists are using CRISPR to produce stem cells that won't cause an immune reaction and can therefore be used to treat macular degeneration.

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Understanding how cells function

Genome editing can be used to speed up complex screening processes in research. For example, a researcher might want to know what genes contribute to a specific disease.

Using CRISPR and cells grown in the lab, it is possible to edit many genes at the same time, and then test what effects these edits have on the cells.

Scientists are developing a CRISPR screening platform that they can use to study diseases such as cancer and arthritis.

They are interested in finding which genes cause disease when they are changed, because it makes it easier to develop better drugs and treatments.

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Appendix B: Future possibilities of genome editing handouts

Future possibility 1: Genome editing for medical purposes

- Some diseases are **caused by, or are influenced** by, genes.
- Genome editing has the **potential to treat disease** by editing out the 'faulty' gene.
- There are two possible types of genome editing in humans.
  - Heritable **(germline)** – changing the genes passed on to children and future generations, by editing reproductive cells and early stage embryos (through sperm and eggs)
  - Nonheritable **(somatic)** – editing faulty genes in a way that is not passed on through generations (not through sperm and eggs)

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Future possibility 1: Genome editing human embryos

- Last year in China, a scientist edited human embryos to make them resistant to the HIV virus.
- The first genetically edited children were born in 2018 – named Lulu and Nana. This is currently illegal in the UK.
- Editing the gene that HIV uses to infect a person's cells, may accidentally cause other '**side-effects' which could be harmful** (such as a weaker immune system) or **beneficial** (such as increased intelligence) – we **cannot predict with certainty.**
- Because the embryo was edited, the changes made could be passed on to the twin's descendants and their descendants and so on.
- Scientists heavily criticised this work, which was conducted poorly. It could be possible to bypass issues this raised by being more careful, or by only using somatic genome editing.

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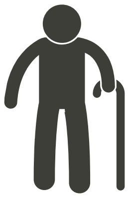
Future possibility 2:
Changing traits in humans

- In the far future, it may be possible to use genome editing technology to change or **enhance traits** in humans like eyesight, strength or endurance
- Allow parents to choose their offspring **hair colour, eye colour and** some even think **intelligence**
- Or increase **human strength or endurance**, thus creating super athletes or humans who can survive for longer in extreme and hazardous working environments like deep-underwater, or space
- Some predict it may even be possible to **slow down ageing**



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Future possibility 3:
Genome editing animals

- GE could result in… **healthier animals and contracting fewer diseases**
  - For example, chickens could be made resistant to bird flu, but the edits may have other effects on the cells of the chickens

- Or more **environmentally sustainable farming**
  - Animals may need less space, or require less feed if they are more resilient, but some worry this could negatively affect animal welfare

- GE animals could bring about **medical benefits**:
  - GE mosquitos could be prevented from carrying diseases like malaria, but some worry about effect of releasing GE animals into 'natural' populations.
  - GE pig organs will be used in human transplants in the next five years – to help rejection by our antibodies / immune system to a foreign tissue

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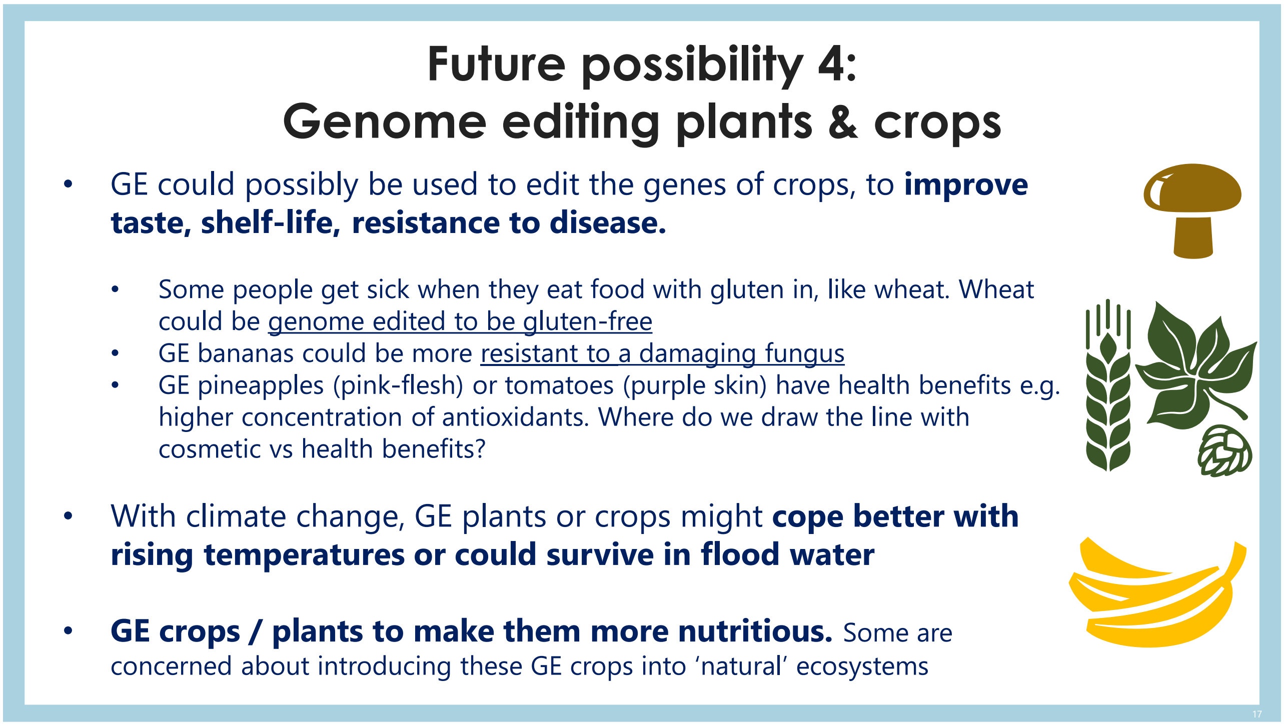
Future possibility 4:
Genome editing plants & crops
• GE could possibly be used to edit the genes of crops, to improve taste, shelf-life, resistance to disease.
• Some people get sick when they eat food with gluten in, like wheat. Wheat could be genome edited to be gluten-free
• GE bananas could be more resistant to a damaging fungus
• GE pineapples (pink-flesh) or tomatoes (purple skin) have health benefits e.g. higher concentration of antioxidants. Where do we draw the line with cosmetic vs health benefits?
• With climate change, GE plants or crops might cope better with rising temperatures or could survive in flood water
• GE crops / plants to make them more nutritious. Some are concerned about introducing these GE crops into 'natural' ecosystems

Appendix C: Information shown about the art piece

Emilia Tikka constructs a possible future for humanity in which aging is a choice. A scientific paper reported that cells become "rejuvenated" when four genes are partially activated. In mice, this even led to longer life spans.

What would it be like if humans could regulate their own genes with high precision and reverse the aging process?

"I imagine someone would have to inhale the mixture from the vials – including CRISPR-Cas9 – on a daily basis to stay young"

They show a couple: The man has been preserving his youth for decades, while the woman has let nature take its course.

Appendix D: Glossary of Terms

Term	Definition
CRISPR/Cas9 genome editing technique	A recently discovered genome editing technique adapted from a naturally occurring genome editing system in bacteria. This technique is cheaper, faster, more efficient and more versatile than preceding available techniques
Designer babies	Children who have had their genome-edited for desirable traits, including removal of life-threatening genes/mutations and/or cosmetic changes such as changes to eye colour or height
Epigenetics	The study of inherited traits caused by mechanisms other than changes in the underlying DNA sequence
Gene	A section of DNA containing information to make proteins
Genome	All of the genes in an organism's DNA
Genome editing	The act of editing a gene/s within an organism's genome, which could be one specific gene or multiple genes at once
Genome editing technique	One specific method of editing the genome, such as the CRISPR/Cas9 genome editing technique
Genome editing technology	The entire suite of genome editing techniques that are available for scientists to use which give scientists the ability to change an organism's DNA
Germline genome editing	Refers to editing the genomes of embryos, sperm and eggs, so that changes made would be inherited by future offspring
Laddering effect	An effect whereby the acceptability of something (in this case genome editing technology) increases with greater usage, or it becomes more acceptable in different contexts with greater usage

Off-target effects	Changes made unintentionally to DNA by genome editing, often due to the similarity of DNA sequences elsewhere in the genome
ORION	Open Responsible research and Innovation to further Outstanding kNowledge - a four-year project funded by the European Union's Horizon 2020 Research and Innovation Programme (agreement No. 741527) under the Science with and for Society (SwafS) Programme, to build effective cooperation between science and various sectors of society. A consortium of organisations conducting, funding and supporting research across Europe are participating in the project
Somatic genome editing	Refers to edits in cells other than embryos, sperm and eggs, so that changes made to the genome are not heritable.
Xenotransplantation	The act of transplanting tissues or organs between members of different species

Appendix E: Advisory Group members

International Advisory Group members

Name	Organisation	Role
Simon Burrall	Involve Foundation (UK)	Senior Associate
Marta Agostinho	EU-LIFE	Coordinator
Luca Franchini	Fondazione ANT (Assistenza Nazionale Tumori) Italia Onlus (Italy)	Psychologist (MSc. Social, Work and Communication Psychology)
Annette Leßmöllman	Faculty of Humanities and Social Science, Karlsruhe Institute of Technology, (Germany)	Vice-Dean
Michael Wakelam[22]	The Babraham Institute (UK)	Director
ORION staff leading this project at participating organisations members of the Advisory Group:		
Nikola Kostlánová	Central European Institute for Technology, CEITEC (Czech Republic)	Scientific Secretary
Luiza Bengtsson	Max-Delbrück-Centrum für Molekulare Medizin in der Helmholtz-Gemeinschaft, MDC (Germany)	Wissenstransfer and Outreach
Maria Hagardt	Vetenskap & Allmänhet, VA (Sweden)	International Relations & Communications Manager
Stephanie Norwood	The Babraham Institute (UK)	Public Engagement ORION Open Science Project Officer (maternity cover)

[22] Professor Wakelam sadly passed away on 31st March 2020, before the publication of this report.

Appendix F: Babraham Institute & Ipsos MORI Project Team

The Babraham Institute Public Engagement Team

Name	Organisation	Role
Emma Martinez-Sanchez	The Babraham Institute	Public Engagement ORION Open Science Project Officer
Stephanie Norwood[23]	The Babraham Institute	Public Engagement ORION Open Science Project Officer (maternity cover)
Tacita Croucher	The Babraham Institute	Public Engagement Manager
Hayley McCulloch[23]	The Babraham Institute	Public Engagement and Knowledge Exchange Manager (maternity cover)

Ipsos MORI project team

Name	Organisation	Role
Michelle Mackie	Ipsos MORI	Research Director and Head of Ipsos Dialogue
Graham Bukowski[23]	Ipsos MORI	Associate Director
Sarah Castell	Ipsos MORI	Head of Futures
David Hills	Ipsos MORI	Senior Research Executive
Holly Kitson	Ipsos MORI	Senior Research Executive
Amber Parish	Ipsos MORI	Project Administrator

[23] These individuals left the Babraham Institute / Ipsos MORI prior to the reports being published

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About Ipsos MORI's Social Research Institute

The Social Research Institute works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. This, combined with our methods and communications expertise, helps ensure that our research makes a difference for decision makers and communities.