Ipsos

Public dialogue on genome editing

UK country report

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

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ORION open science

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We would also like to thank all of 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 UK events are listed in Appendices A and B.

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 and UK Review Group who have agreed to be named in this report are listed in Appendix G. The Babraham Institute's Public Engagement Team and the project team at Ipsos MORI who authored this report are listed in Appendix H.

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

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

Executive Summary

The ORION consortium[3] 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[4] technology in ORION research institutions. Events were held in four countries where ORION partner organisations are located; the UK, Germany, Sweden and the Czech Republic. **This report details findings from the dialogue held in Cambridge (UK), which was led by the Babraham Institute.** During the events, members of the public discussed current research applications of genome editing technology, possible future uses, and explored the best ways for ORION partners to engage with the public about genome editing.

Views on key societal challenges and solutions

Participants were invited to think about key challenges and problems currently facing society and how those challenges could be solved. Participants identified main, interconnected areas: **economic inequality and poverty, societal division and polarisation, and climate change and food production.** While none of the participants mentioned genome editing technology as a solution to these problems, they proposed solutions including technology to develop more accessible foods and the development of laboratory-grown foods reducing the need to farm. **Thus, participants suggested solutions that genome editing technology may be able to help to deliver**, even before they had learnt about the technology.

Views of basic research and genome editing techniques

Participants had some understanding of central biological concepts, but were mostly unaware of terms like 'genome editing' and the genome editing technique CRISPR/Cas9. There was a limited understanding of basic or fundamental research.[5] Despite this, participants were **supportive of genome editing to be used in basic research** as it was felt that the acquisition of new knowledge would help to **ensure the realisation of real-world benefits from the techology** while reducing the likelihood of negative consequences arising from its use. There was also concern about genome editing being used irresponsiby, and **the concepts of safety, ethics and fairness were associated with decisions around how the technique should be deployed**.

Views of possible future uses of genome editing

Participants discussed a range of future possible uses of genome editing applications. There was **positivity about the potential applications of genome editing to improve health and to tackle diseases like cancer.** Participants were supportive of non-heritable 'somatic genome editing'[6], but felt less supportive of heritable 'germline genome editing'[7] as they worried about potential long-term unknown detrimental consequences to people whose genomes have been edited. They were also unsupportive of the use of the technology for

[3] 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.

[4] 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.

[5] Fundamental biological research, such as understanding how cells work, which may or may not eventually lead to practical applications.

[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.

human enhancement or changing cosmetic traits. There was some support for genome editing of plants/crops or animals and livestock where this could help tackle food shortages or promote sustainable farming. However, there were concerns about the unknown effects of these changes to the environment.

Communication and engagement

Participants suggested the scientific community should create an agreed and respected documentation showing the development of the technology, where the research is currently at, and the possible future uses and benefits and risks. Participants felt that there should be **clear messaging about what is and is not currently allowed regarding the use of genome editing technology**. They felt it is important for communications to address concerns and questions regarding the principles they hope will guide the deployment of the technology, namely: **social justice, equity, and fairness**.

To bolster perceptions of transparency, scientists could **communicate about their failures and what has not worked as well as their successes.** Another way to build trust is to **show examples of scientists talking about genome editing from their own perspectives**. Participants were clear that any information about genome editing presented to the public should use **clear and simple language.**

Which methods work best for engaging the public about genome editing techniques

Participants felt that all the methods of public engagement had pros and cons, therefore a combination of approaches is needed. They felt that **public dialogue or deliberative workshops are highly effective methods of engaging the public** but have only a limited reach. **Participants suggested that a combined approach of online and televised communications** would have a wide reach among the general public and therefore should be used to inform as many people as possible. Also, given that participants felt the impact of the technology could be so transformative to society, **they suggested that children should be taught about this topic in school.**

Participants were shown an art piece – *ÆON* – depicting a hypothetical future scenario where genome editing technology is used to preserve youth.[8] **The art piece successfully encouraged people to discuss potential issues related to genome editing technology**. While art pieces like *ÆON* are effective in engaging audiences, we recommend that there should be additional information provided alongside the art, and it is important to recognise that this medium will not appeal to everyone and therefore has a restricted reach.

Key conclusions

Participants were optimistic about the potential impact that genome editing technology could have, particularly in relation to tackling diseases. They did, however, seek reassurance around how the technology will be regulated and how potential negative effects would be minimised. Participants felt it was important that the current progress and regulations of the technology were communicated, and that failures of uses of the technology were discussed alongside successes to foster public trust. There was a desire that communications about genome editing should have a wide reach among the general public and it was felt that the best way to do this was through a combination of methods of engagement, such as online, on TV and through education.

[8] More information about this art commissioned by one of the ORION partners (MDC) can be found here: https://www.emiliatikka.com/new-page-1

1 Background, objectives, and method

1.1 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 country report details findings from the dialogue held in the UK. Individual country reports from the other three countries are also available, as well as an overall summative report that synthesises findings from dialogue events in all four countries.[10]

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

1.2 Aim 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, and to shake up an area of research, or to 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.

1.3 Method

The format of the dialogue within each country had important input from 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 each participating organisation and their networks joined in the dialogue events to provide specific knowledge and expertise.

The dialogue method used in the UK is outlined below and has been replicated across the other three countries to support a comparative analysis of the entire dataset, leading to the production of a synthesis report that summarises the main conclusions and similarities and differences across countries.

1.3.1 Governance

International Advisory Group:

An international Advisory Group was convened to provide oversight and governance of the overall project. Advisory Group membership consisted of stakeholders with knowledge and expertise in genome editing, the ethical issues associated with the technology, and science communication as well as ORION staff from each of the four partners involved in the project. A list of Advisory Group members who have agreed to be named in this report can be found in Appendix G.

Review Group:

A Review Group was set up within each country to help frame the public dialogue materials to reflect the national and institutional context. The UK Review Group membership consisted of Babraham Institute scientists, Insititute funders, a civil servant from the Department for Business, Energy and Industrial Strategy, and the ORION staff leading the project at the Babraham Institute.

Project Management Team:

ORION staff within the Public Engagement team at the Babraham Institute worked directly with Ipsos MORI to coordinate and manage the project on a day-to-day basis, reviewing initial drafts of the research materials, sending these to the Advisory Group and Review Group for comments and final approval.

The groups outlined above were involved in different capacities in reviewing the following elements within the project:

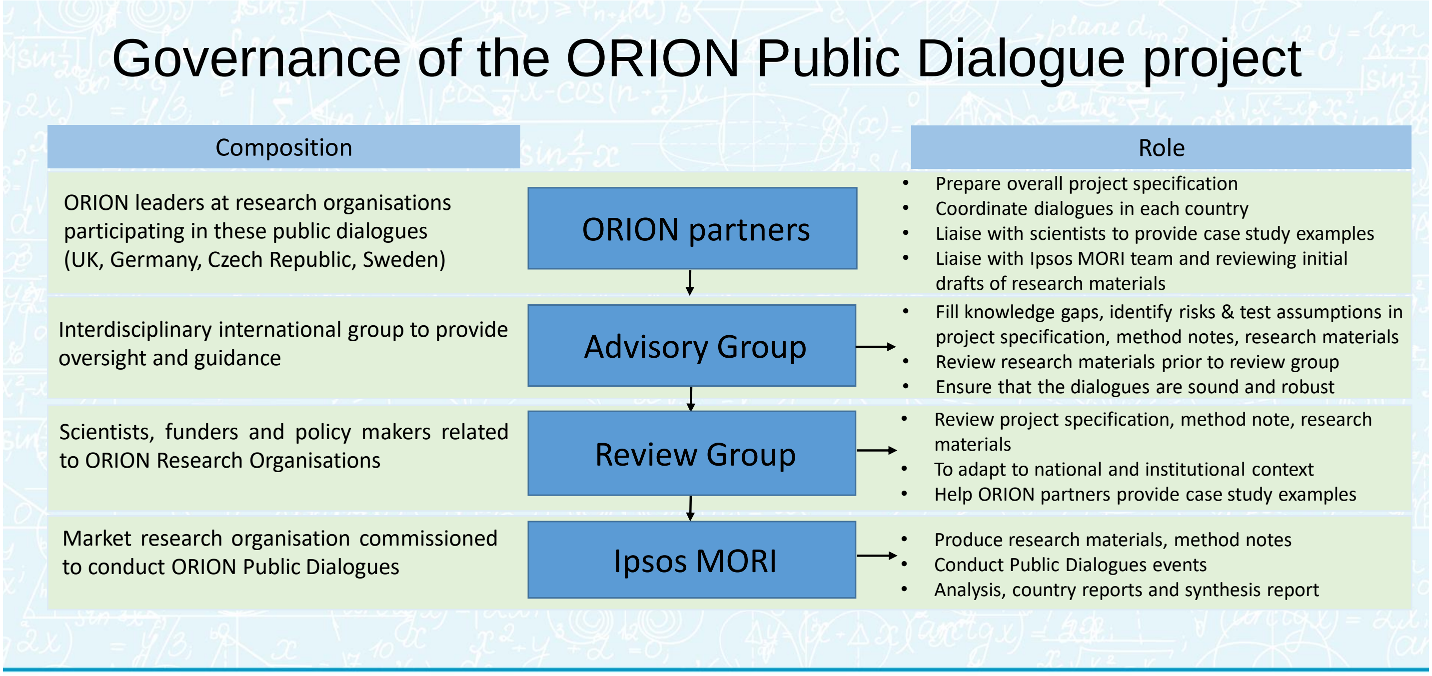
- Project specification – Initial document produced by the ORION consortium that outlined the background, context and rationale behind the project, the aims, objectives and proposed methods, the expected outputs and outcomes, anticipated risks, and proposed method of disseminating findings. It also outlined the proposed purpose and method of evaluating the project.

- Method note – Document produced by commissioned organisation Ipsos MORI in response to the aforementioned project specification and discussions held between Ipsos MORI and the Babraham Institute. This method note outlined a detailed plan for the approach taken to the project, including the planned recruitment process, event design and content, analysis and reporting of the data and staffing and management of the project.

- 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 at the Babraham Institute.

The diagram below depicts the governance structure of this project.

Figure 1.1: Governance structure of public dialogues



1.3.2 Public dialogue workflow

The project proceeded in the following stages:

1. The ORION consortium commissioned Ipsos MORI to run a project consisting of 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 workshop with stakeholders.

3. A workshop was held at the Babraham Institute with stakeholders including experts in genome editing, ethics, law, and science communication and engagement.

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

5. The research materials were initially reviewed by the Babraham Institute and adaptations were made by Ipsos MORI. The Advisory Group commented on a revised set of materials and further changes were made. The Review Group within each country reviewed the materials before they were finalised.

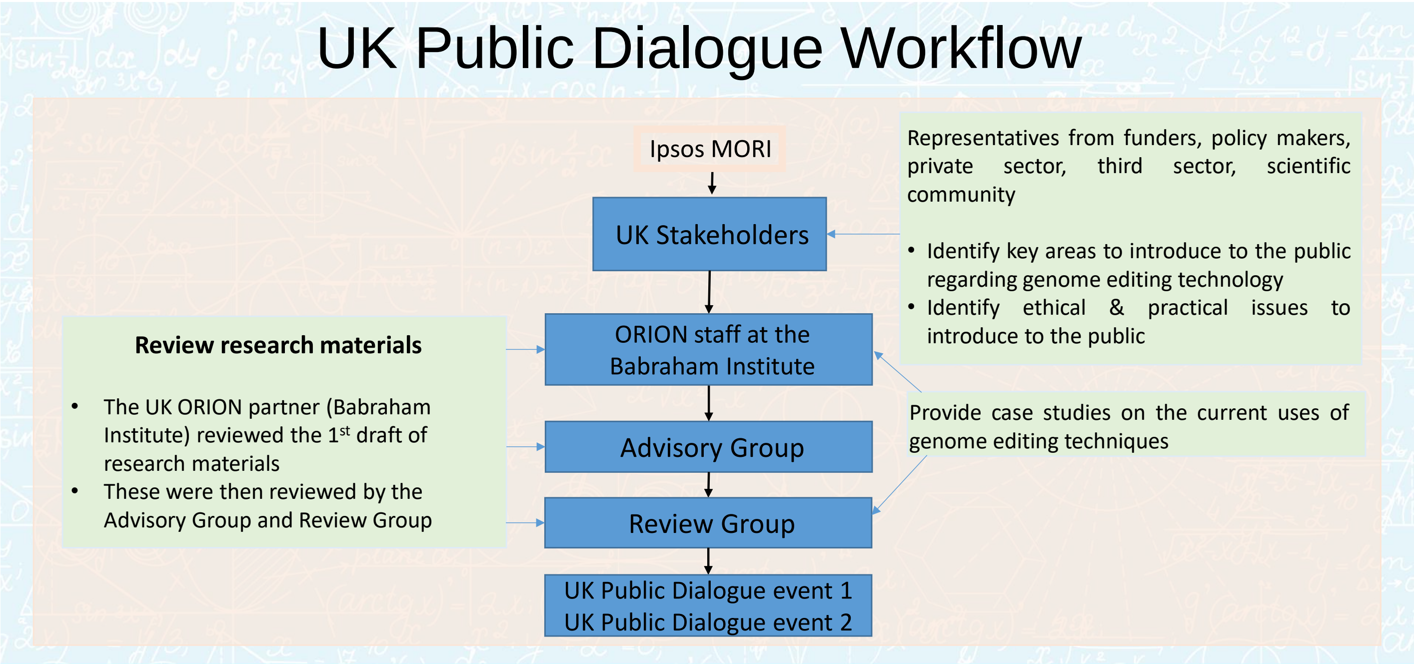
6. A pair of public dialogue events were held with members of the public in the centre of Cambridge.

7. Findings from these events were written up into a report and review by Babraham Institute ORION staff and scientists.

8. An overarching synthesis report pulled together findings from across the four countries including similarities and differences across them.

The diagram below depicts each stage of the process of this project.

Figure 1.2: Workflow of UK Public Dialogues



1.3.3 Stakeholder workshop

A workshop was held on 10th September 2019 at the Babraham Institute with 12 internal and external stakeholders (i.e. people with a vested interest in genome editing technology, some working at the Babraham Institute and others working for other organisations). The purpose of this stakeholder workshop was to gather diverse insight for the design of the materials to be shown during the public dialogue events. Participants were identified by the ORION staff at Babraham Institute, in collaboration with Ipsos MORI, and included a range of experts who brought a perspective on the technical and ethical issues associated with genome editing. These included scientists using genome editing techniques and other experts who expressed views from a legal, ethical or policy context. A breakdown of the stakeholders involved in the workshop is provided in the table below, and a list of stakeholders who agreed to have their names and roles presented in this report can be found in Appendix A.

Table 1.1: Breakdown of stakeholders who attended the UK stakeholder workshop

Stakeholder Type	Stakeholder Sub-type	No. Stakeholders
Experts in life sciences	Researchers/academics	2
Experts outside of life sciences	Legal Expert	1
	Healthcare Ethics Think Tank	2
Funders	Research funder	1
Industry representatives	Agricultural scientist	1
	Pharmaceuticals	2
Policy makers	Policy Maker	1
Public Engagement Specialists & Journalists	Public Engagement Specialist	1
Representative bodies	Food Science	1
Total number of Stakeholders: 12		

1.3.4 Public Dialogue events

Two dialogue events were held in the UK with members of the public to discuss genome editing technology. Both took place at the Michaelhouse Centre, in the centre of Cambridge. Thirty one members of the public attended the first event and thirty of these attended the second event.

Recruitment of participants to the events was undertaken by the qualitative research recruitment specialists Criteria, a sub-contractor of Ipsos MORI. Ipsos MORI developed recruitment materials which Criteria's staff used to recruit participants to the events. 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 in participating.

Recruitment was conducted face-to-face in and around the Cambridge area. Recruiters approached members of the public and asked if they would be interested to participate in the research. If so, information would be provided to them on what the research was about and when and where the events were taking place. The recruiter would then ask questions using the screening questionnaire to collect information about participants. At this stage, participants were also given a privacy policy outlining who Ipsos MORI and the Babraham Institute are, what personal data was being collected from them (with their consent), how this would be used, who the data would be shared with, and what their legal rights were.

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 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 table below provides a breakdown of participants by these characteristics.

Table 1.2: Breakdown of participants who attended the UK public dialogue events

Location	Urban location	10
	Suburban location	13
	Rural location	8
Gender	Male	16
	Female	15
Age groups	18-30	8
	31-44	7
	45-64	10
	65+	6
Ethnic background	White	20
	BAME	11
Child status	Children at home	14
	Children sometimes at home	5
	Children have left home	4
	No children	8
Employment status	Retired	6
	Unemployed	4
	Employed (full or part-time)	21
Attitudes to genome editing	Comfortable with the concept	22
	Uncomfortable with the concept	7
	Don't know	2
		Total number of Participants: 31

Participants were split into three discussion tables per event, with a mix of ten participants sitting on each table (eleven participants sat on one table at the first event). Each participant was randomly allocated to a table, and sat in different groups at the two events.

Experts (people who have a vested interest in genome editing technology through their work, though not necessarily scientists using the technology) attended each of the events and were involved in the table discussions. The role of the experts was firstly to answer questions participants had about genome editing technology – this could involve for example explaining how genome editing techniques work, how the technology might be used within basic and applied research. Secondly, experts spoke about their own work, which may have been around using genome editing techniques in a laboratory as a scientist or speaking about genome editing technology from a historical, ethical or legal perspective. Thirdly, experts were encouraged to comment where appropriate during the discussions on each table, for example by providing relevant information to inform the discussion. Experts were encouraged to play a neutral role in the discussions (for example by not taking sides in debates about ethical issues).

Experts were either stakeholders who had attended the stakeholder workshop or were scientists identified by the ORION staff at the Babraham Institute. Three experts attended the first event, and four experts attended the second event. A list of experts who attended the events and who have agreed to be named in this report can be found in Appendix B.

Event 1: The first event was an evening workshop that ran between 6.15pm and 9.15pm on Thursday 24th October 2019. The goal of this event was to give participants sufficient information 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, genes, the genome, and proteins, thus 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 the Babraham Institute's research using genome editing.

Event 2: The second event was a day-long workshop running between 10am and 4pm on Saturday 2nd November 2019. During this event, the case studies outlining examples of the Babraham Institute's research were re-introduced to remind the participants about the type of research conducted by the Babraham Institute, 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 hypothetical far off scenario where genome editing technology has enabled the slowing down of the ageing process.

Post-events analysis: With participants' consent, discussions at the events were recorded and notes were taken by professional notetakers from the Ipsos MORI team. This information was used in a thematic analysis of the events and an analysis session was held with the Ipsos MORI moderators to discuss emerging findings. Themes were reviewed using Excel and paper-based clustering of ideas as well as the detailed notes and audio recordings of each session along with the flip chart and post it note exercises created by participants. This work enabled key themes to be developed, which are laid out as findings throughout this report.

1.3.5 Methodological limitations

Qualitative research is designed to be illustrative, detailed and exploratory. It provides insight into perceptions, feelings and behaviours rather than being designed to be statistically representative of the wider population.

There are some factors that we recognise had the potential to sway or bias participants' views and attempts were made to mitigate these:

- The presence of experts in the room who work in the field of genome editing could have influenced participants' views or made them less likely to be critical of the technology being presented to them. The possibility of this occurring was mitigated by:
  - firstly encouraging participants at the outset of the diagloue events to be open in their views and informing them that there were no 'right or wrong answers',
  - secondly, participants were invited to share their views directly with moderators prior to the experts answering questions or providing additional information,
  - thirdly, experts were provided with guidance about their role prior to the events, which asked them to play a neutral role in the discussions, not to take sides, and to allow the participants to speak before they did themselves, and finally;
  - experts were chosen to demonstrate a range of perspectives on genome editing; some of the experts (but not all of them) worked for the Babraham Institute itself.
- Paying participants financial incentives for participating may have influenced participant opinions and lead to response bias. Paying incentives compensates participants for their time and effort and makes it much more likely they will remain involved and committed as they will feel compensated. Paying incentives to participate also helps to overcome a skewed sample, where if people willing to participate without compensation were recruited, the views of less engaged citizens could be missed. The possibility of the use of incentives biasing responses was mitigated by making clear that incentives came from the organisation independently delivering the work (Ipsos MORI) rather than the Babraham Institute itself. Participants were also recruited according to quotas, including sociodemographic segment, to try and ensure participants reflected a broad range of financial backgrounds.

2 Views of key challenges facing society and solutions

At the start of the first dialogue event, participants were invited to think about key challenges facing society, how they imagine those challenges could be solved, and what role technology could play. This allowed people to feel comfortable discussing issues and also revealed if their stated individual societal challenges overlapped with the opportunities that could be realised through research involving genome editing.

2.1 Public views of key challenges facing society

Economic inequality and poverty were seen as key challenges facing society. There was concern from participants about a perceived imbalance of resources – specifically money, food, and medicines – and a society of have and have-nots. This was reflected later in the event when discussing the future use of genome editing technology as there were concerns that genome editing applications could create a future of genetic inequalities, which was a worry for participants.

"We thought of two [challenges facing society], (…) distribution of wealth and crime."
Event 1 Cambridge

Societal division and polarisation was a prominent concern. Brexit and the rise of populism and identity politics[11] were also raised as key problems in society and the effect of this was felt to be a more fractured society. There was concern that a far-off future of genome editing would change perceptions around what it means to be human and as a result it would lead to further marginalisation of certain groups in society.

Climate change and food production were often seen as interconnected problems. Almost all felt that the effects of climate change would become more acute as a result of efforts to feed a rising population. Later in the discussions, participants saw genome editing technology having potential benefits to tackle environmental concerns and food shortages, but fears of over-population remained as a result of perceived improvements in medicine.

"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

Several societal challenges relating to health were raised. For example, participants viewed disparities in access to healthcare as problematic, which links to concerns about economic inequality. More specific challenges relating to health included the prevalence of disease, mental health, increased antibiotic resistance, and reduced take-up of vaccines.

[11] Political alliances and beliefs based on groups people see themselves as belonging to according to aspects of their identity, such as gender, race, or class.

"Access to healthcare, people in different areas have different access and availability."
Event 1, Cambridge

2.2 Spontaneous views of solutions

Some of the solutions presented by participants to the challenges they identified were political and societal. For example, there were perceptions that the current economic system could be changed by greater sharing of resources, to address inequalities. These resources could be used to provide support in deprived areas, such as helping to build infrastructure in developing countries. Participants also thought funding should be used to try and ensure there is greater access to food and healthcare for all, for example by reducing the costs of medicine.

None of the participants mentioned genome editing technology as a solution to the problems they identified, however they did propose solutions that genome editing technology might help to deliver. For example, technology was viewed as providing solutions to challenges around food. This included developing foods that were accessible to more people, for example those that could grow throughout the year rather than being seasonal. Another suggested use of the technology was the development of laboratory-grown foods such as meat or meat substitutes, which reduces the need for farmland and has potential to reduce greenhouse gas emissions. Later on in the event participants discussed potential benefits of using genome editing technology to deal with these issues, such as genome-edited crops that were easier to grow or had a longer shelf-life, and genome editing livestock that were more resistant to disease or could be farmed in a more environmentally sustainable way.

Technology was also seen as pivotal in improving health and tackling disease. Participants predicted that technological developments would help to improve diagnoses through new techniques and equipment and could improve access to healthcare professionals through video conferencing and other innovative communication methods.

"It's like through improved technology, we can detect more or early stage."
Event 1, Cambridge

"It needs to be a lot more research into what's causing it [diseases like cancer]. What we are doing differently from 40 years ago, there just seems to be increase in diseases especially with cancer."
Event 1, Cambridge

3 Views of basic research and genome editing techniques

Prior to the public dialogue event in Cambridge, Ipsos MORI conducted a workshop with Babraham Institute stakeholders with expertise in genome editing from various backgrounds (bringing scientific, ethical, legal and policy perspectives). This stakeholder workshop helped to ensure that at the dialogue events, the public were presented with information and perspectives collated from a wide range of sources. The purpose of this workshop was to establish what information experts felt the public would need to engage with the different ways researchers at the Babraham Institute use genome editing, as well as the technical and ethical issues arising from its use.

Stakeholders felt that the public should be introduced to basic biological concepts before learning about genome editing technology. Therefore, participants were invited to complete a quiz, which informed them about key biological concepts in a fun and engaging way, before introducing them to examples of the Babraham Institute's research involving genome editing technology.

3.1 Participants' starting points

Participants overall had a vague understanding of key biological concepts such as DNA, genes, cells; terms like 'genome', 'genome editing', and CRISPR/Cas9 resonated even less.

Participants had some understanding of terms such as 'DNA', 'cell', and 'genes', with several people bringing up consumer genetic testing kits. However, only a few understood what roles these components play in the biological processes of organisms. A minority, familiar with the terms 'genome' and 'genome editing', had a personal interest in contemporary developments in science and were fairly informed about genome editing.

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

Participants were then given an overview of what genome editing technology is and how it works by moderators, who showed a short animated video to help to explain this.[12] Upon learning about genome editing technology, participants' first impressions were that it had potential to be a game changer in relation to health, wellbeing, and food production, but at the same time there was real concern about the possible negative consequences. There was a strong desire for the realisation of real-world benefits associated with genome editing technology, and the effect of this was firm support for research that delivers better understanding of genome editing applications and the impact of genome editing on society, organisms and the planet. There was also strong support for genome editing to be used in basic research as it was felt the acquisition of new knowledge would help to ensure the realisation of benefits, while reducing the likelihood of negative consequence arising from the use of this technology.

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

"There are diseases out there that are horrible. If we could do something about it, will that be cheaper to help us out than the cost of day-to-day maintenance for the person, and the pain the person goes through?"
Event 1, Cambridge

After discussing the wide uptake of the revolutionary CRISPR/Cas9 genome editing technique in research laboratories however, there was concern that not everyone in the scientific community would use this technology in a responsible way; the concepts of safety, ethics and fairness were associated with decisions around how the technology should be deployed.

"It comes back to the trust. Would you trust the scientists? We have to trust somebody."
Event 1, Cambridge

Participants were very clear that negative and unintended consequences arising from the use of genome editing should be avoided at all costs. Here, participants stated that rules governing the use of genome editing in basic research and upstream research such as medical research should be adopted by the global scientific community. At the heart of this was a desire for the robust testing of the effects of genome editing in basic research so as to ensure safety and efficacy of the intended changes to the genome, and a globally agreed set of genome editing behaviours that deliver fair and ethical outcomes. Participants concluded that these outcomes should not undermine social justice, fairness and human rights. Of particular concern was the potential for genome editing technology to be used in humans to choose desirable traits, which was seen as possibly undermining these principles (views of this possible future use of genome editing are discussed in detail in section 4.1.5).

"People with money in the future will say they want blue-eyed blonde-haired baby and will pay."
Event 1, Cambridge

"As we were talking about regulations, it should only be used for curing problems rather than adding new features to the person."
Event 1, Cambridge

3.2 Views of basic research using genome editing technology

It was outlined that the Babraham Institute conducts early-stage, basic research aimed at understanding biological processes underpinning healthy ageing, which may or may not lead to immediate practical applications. This explanation improved participants' limited understanding of basic research, and to value the acquisition and sharing of knowledge and understand how genome editing technology has the potential to address many of the societal challenges that they had originally identified.

Participants understood that genome editing technology could lead to scientific and clinical developments but struggled to understand that the aim of basic research could be exploratory. Because of their limited understanding of basic research, participants made judgements about the benefits and risks of the technology based on what impact it could have if it were applied in the real world.

When participants learned that newer genome editing techniques such as CRISPR/Cas9 are more accurate and more efficient than previous genome editing methods, they were encouraged to know it was being used widely in UK labs. This was because they felt that a lot of in-depth research needed to be done before genome editing technology could be used in an applied way.

"There's a lot more research that needs to be done. There are lab tests, but introducing [this genome editing technique] to a natural environment, what effect is that going to have?"
Event 1, Cambridge

Participants were shown three examples of the Babraham Institute's basic research using genome editing in the form of case studies presented as a one-page handout. Participants discussed these in the first event and revisited them in the second event. These case studies are outlined below, and the full case study handouts shown to participants can be found in Appendix C.

Case study 1: Editing model organisms – this case study outlined research that scientists at the Babraham Institute are conducting using genome editing to identify proteins that control different functions of cells. It explained that genome editing could be used to modify the DNA of model organisms, such as mice, to try and better understand the role proteins play in how cells grow, reproduce, what jobs they do and how long they live for.

Case study 2: Epigenetic markers – this case study explained that the function of genes can be switched on and off by chemical groups attached to the DNA, called epigenetic marks, and that scientists at the Babraham Institute are using genome editing techniques to study how epigenetic marks in a mother's egg cells can affect how the DNA is read and used in her children's cells.

Case study 3: How the immune system works – this case study explained that the immune system produces antibodies to defend us from bacteria and viruses, but that our immune system works less effectively as we age. It outlined that Babraham Institute scientists are using genome editing techniques to try to better understand what causes our immune system to decline with age.

3.2.1 Case study 1: Editing model organisms

Participants struggled to understand the case study and the role of genome editing within it, so had questions about the technology. For example, they wanted a better understanding of the role of proteins in organisms.

"They are using big words and throwing information at you and people need that. Before I came here I'd never heard of this but I have more understanding…they don't normally use the right words…if they really take the time to educate people, they can give information."
Event 1, Cambridge

Participants could see the benefit of this type of research, even though they did not fully understand how it worked and considered that there was value in doing exploratory research. This was particularly true for this case study as it reduced participants' concerns around the safety of the research, since trials are initially carried out on mice.

"It's essential, a requirement to understanding the system that you're trying to fix. You need understanding of it first. It's essential."
Event 1, Cambridge

Discussions focussed around how the technique might work in practice to try and understand the broader implications of the technology. For instance, if scientists were to develop a treatment for slowing down the ageing process, participants pondered what the impact would be on the National Health Service (NHS) and people's health if it became widely available.

"From my point of view, if the first step is successful then people live longer – we now have an aging population so it could help manage people when they reach that age because the vast majority of people in the NHS are elderly people, so if we can help it is not just about taking strain of the NHS but about improving people's quality of life at that point, so I think it's good."
Event 1, Cambridge

"You can make more specific drugs to target specific proteins."
Event 1, Cambridge

However, the value of the research was seen in terms of there being some eventual end benefit for humans and there was some optimism about the potential for using this research to better understand diseases like cancer.

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

There is already existing research on public opinion regarding the use of animals in research[13] so this was not a primary objective of this research. Participants could tolerate animal models being used in research if only done when necessary for creating treatments that are safe for use in humans and assuming the research did not cause unnecessary pain.

3.2.2 Case study 2: Epigenetic markers

Participants found it difficult to understand what this research was trying to investigate, and therefore raised questions about how genome editing techniques would work in practice when discussing the case study. Generally, there were questions about what chemical markers are and how they work, as well as what the term 'epigenetic' meant (generally applied to mean changes in the activity of a gene that occur without changes to the DNA sequence of the gene).

[13] https://www.ipsos.com/sites/default/files/ct/news/documents/2019-05/18-040753-01_ols_public_attitudes_to_animal_research_report_v3_191118_public.pdf

"Is epigenetic the same as changing that genetic DNA with CRISPR, cutting it out? Is this the same [as that] or is it just studying?"
Event 1, Cambridge

"These [scientists] study epigenetic marks, I haven't a clue what are they, where do they come from...is it to do with lead in the air, is it to do with pollen?"
Event 1, Cambridge

Participants also raised concerns about the decision making and regulation of this type of research. Concerns included how decisions would be made on what genes would be switched on or off to combat disease, who would make these decisions and what the end point would be– when do you stop? There was also worry about people making unhealthy choices thinking that they could just edit the effects out later on.

"If [a technique that could change how epigenetic marks affect human DNA] is developed, it is going to be inevitable. I don't think it will be stopped at a certain point. I think there will be...doctors will go off and sell things to wealthier people. I don't think it will ever stop at a specific point."
Event 1, Cambridge

There was positivity that this technique would be non-invasive and preventative (as opposed to reactive), particularly if it could prevent children getting ill through DNA changes being passed onto offspring. But along with this there was acknowledgement that this conflicts with individual choice, and that unknown changes could also be caused, or desirable features knocked out.

"I've got psoriasis. I've got four kids. If I had a way of knowing they didn't get it, I'd definitely do it."
Event 1, Cambridge

"What about the potential for people born with disabilities to excel in specific areas because their disabilities force them in that direction?"
Event 1, Cambridge

There was surprise about the effect environmental factors can have on us (the case study discussed how our genes work and can be affected by factors in the environment that are translated inside the cells as chemical 'marks' that get permanently stuck onto DNA) and a feeling that research into this area was important; in particular, if such research was helping to increase knowledge about the importance of diet, this knowledge should be shared with the public so they could make healthier choices.

"If it is identifying how diet can affect [us], can we use that information at that stage rather than going to genetic modification?"
Event 1, Cambridge

"If I understand, once they switch off this gene, the baby comes and avoids genetic disease…are we sure that it wouldn't reverse at some point in that child's life, some environment can cause something, the way we live with pollution, why wouldn't that be the same thing just because they switch off that gene?"
Event 1, Cambridge

3.2.3 Case study 3: How the immune system works

When participants were trying to make sense of this case study, they considered a society where people could live longer, rather than thinking specifically about how cells age over time.

There was concern about societal implications if people could live longer in relation to: overpopulation, inequalities in having access to treatments that may be developed using genome editing techniques, and the impact on world resources like food and water. Concern was also raised as to whether there would be an age limit for these treatments or, if everyone would have access to the technology regardless of their age and whether people could choose when they want to die. Participants argued that regulation would be important, so it is clear who is responsible for these ethical considerations.

"My preference will be to live as long as I could. What effect does it have on other things like feeding the population?"
Event 1, Cambridge

"What age should you reach?"
Event 1, Cambridge

At the same time, participants were clear we need to not just think about making people live longer but peoples' quality of life alongside this. As with the second case study, there was feeling that scientists should share their findings with as many people as possible so they can make healthy decisions and live better.

"This is also ethical. I want all people to have quality of life. So, it's a definite yes [to genome editing techniques being used for this research]. This is a specific issue, but it's concerned with how we age. So, why we evolved in this way, when we change that, other parts will change. We don't know if we change that, how the aging process will change."
Event 1, Cambridge

There was a perception that using genome editing technology in this type of research to learn how to slow down age-related health decline could have beneficial implications for healthcare systems, as this would mean a healthier population and less drain on public health resources. Again, participants saw this as being preventative.

"It will be good. As we get older, we get less pressure on the NHS. It will be cost effective for health services."
Event 1, Cambridge

3.3 Views of different groups and how they differ

- Male participants, under 35 tended to be more positive and accepting of the use of genome editing technology.

"I liked it. I want to be able to change – I have 2 sons. One of them is very overweight. One of them is slim. I want to give them better waistlines."
Event 1, Cambridge

- Those who were older tended to have more worries about it.

"With that story, my worry would always be the rogue. In all professions, there's always a rogue. Is it the first time it's ever happened? Maybe I'm just cynical."
Event 1, Cambridge

"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

"I keep thinking of Frankenstein. He was way ahead of his time."
Event 1, Cambridge

3.4 Implications for the Babraham Institute

Participants were initially unsure of the direct value of the research that was outlined in the case studies using genome editing. This was largely because the participants did not understand the biology behind the case studies and struggled to understand the technical aspects of each example. However, once the purpose of conducting basic research had been explained, participants did value and support this type of research using genome editing. They felt that the research could lead to applied work that had the potential to address some major challenges facing society.

The implication here for the Babraham Institute relates to how it communicates about its work and how this work is framed for the public. Explaining that genome editing techniques are being used by scientists to try to understand the complexities of life and to explore how living organisms can age more healthily may resonate more and derive more support from the public than communicating the technical aspects of the work.

4 Views of possible future uses of genome editing

A key objective of this public dialogue was to explore how the public trade-off the benefits and dis-benefits and potential unintended consequences arising from genome editing. The objective was also to provide an opportunity for participants to discuss the wider implications of genome editing technology. To this end, participants were shown a range of future possible uses of genome editing applications, namely:

- Genome editing for medical purposes – genome editing techniques might be able to help tackle diseases through the use of non-heritable genome editing as well as heritable genome editing. Experts involved in the discussions also introduced the idea of new treatments, such as gene therapies, which are taking place in clinical trials[14], whereby genetic material is introduced into cells to compensate for abnormal genes or to make a beneficial protein.
    - Non-heritable editing for medical purposes ('somatic genome editing'): 'Somatic genome editing' was explained to participants as referring to edits in cells other than embryos, sperm or eggs, so changes made to the genome are restricted to the specific edited cell and not heritable.
    - Heritable editing for medical purposes ('germline genome editing'): Genome editing can also be used to edit the genomes of eggs and sperm, or the embryo resulting from combining these two cell types, so that changes made would be carried on in next generations of humans. Participants were made aware that implanting genome-edited embryos into humans is currently illegal in the UK.[15] They were also informed about the first genome-edited humans, born as a result of the Chinese scientist's He Jiankui illegal research on the embryos of twin girls in 2018.[16]
- Genome editing for human traits – the idea that in the future, genome editing could enhance human traits such as intelligence or endurance, as well as cosmetic traits such as hair or eye colour.
- Genome editing for animals and livestock – genome editing could make animals more resistant to disease, and enable more sustainable farming practices.
    - As part of this case study we also spoke about the possibilities of editing the genomes of insects such as mosquitoes to inhibit their ability to develop and spread malaria, thus potentially bringing about medical benefits.

[14] https://www.discovermagazine.com/health/gene-therapies-make-it-to-clinical-trials
[15] https://www.regulation.org.uk/specifics-gene_editing.html
[16] https://www.the-scientist.com/news-opinion/china-sentences-gene-editing-scientist-to-three-years-in-jail-66881

- Genome editing for **plants and crops** – genome editing can make plants and crops more nutritious and more resistant to disease, as well as alter them cosmetically, for example changing the colour of the skin or flesh of fruit.

For each of these uses, Ipsos MORI created a case study in the form of a one-page hand-out, which gave information about the purpose of the application, its benefits and possible negative consequences. These case studies equipped participants with information that allowed them to weigh up the possible benefits, as well as implications, arising from developing treatments and therapies using genome editing techniques such as CRISPR/Cas9. The handouts shown to participants can be found in Appendix D. These handouts were designed to enable participants to reach some conclusions on acceptable uses and what trade-offs, and under which circumstances, they are willing to make. The experts supported these discussions by answering questions, speaking about research using genome editing, and giving balanced information about possible benefits and negative consequences.

It is important to note that while the Babraham Institute uses genome editing to better understand fundamental biology and how diseases work, the Babraham Institute wanted to know if it should be helping to inform the public about how other researchers and scientists might deploy genome editing technology. For example, others could build on the learning the Babraham Institute has acquired through the use of the technology. Outlined below, we first set out participants' views of possible future uses of genome editing, in order of perceived acceptability with the most acceptable usage first, and then we cover what implications participants thought this has for the Babraham Institute.

4.1 Overall acceptability of different uses of genome editing

4.1.1 Views of non-heritable editing for medical purposes ('somatic genome editing')

When discussing somatic genome editing in humans, participants discussed health conditions in terms of perceived impact on an individual and whether individuals with health conditions are defined by their condition, as well as technical (e.g. safety) and societal implications. In particular, a possible 'laddering effect' was discussed whereby the acceptability of something increases with greater usage, or due to greater usage something becomes more acceptable in different contexts. Should somatic genome editing become commonplace? Does this increase the chance of changing public attitudes, or specifically an increase in public acceptability towards the use of germline genome editing?

There was very limited awareness of what somatic genome editing was but, once explained, lots of positivity in relation to its potential to help tackle serious health conditions. After being provided with information about somatic genome editing, there was real optimism among participants concerning the potential to edit faulty genes that would otherwise cause serious disease, such as cancer. The acceptability of the use of somatic genome editing to tackle such diseases was felt to be obvious, given the life limiting consequences of having such a serious condition.

"I find somatic [genome editing] more appealing, so the individual can decide for themselves when and how they want anything edited, rather than a decision being made from someone's mother. To me, that's quite appealing, especially if their disease is causing them a particular issue, then they can make that decision to address it."
Event 2, Cambridge

Discussions around the use of somatic genome editing for health conditions such as deafness, blindness, Down's syndrome and autism were less clear cut (although it may not be possible or likely to use somatic genome editing to prevent these conditions in reality, the hypothetical possibility was brought up in order to prompt discussion and explore boundaries of acceptability). Some participants, in general these were male, and under the age of 35, came to the view that any kind of health condition that impacts a person's quality of life should be treated using somatic genome editing if the technology allows. However, most were clear that while these conditions can have a serious impact on a person's quality of life, they didn't think that they limited a person in the same way as a terminal disease, and as a result, they felt the decision about whether to use it in these instances lies with those who are affected by these conditions, as well as healthcare specialists.

Thus, participants wanted a mechanism to ensure the public and patient voices inform decisions around its use for certain health conditions. As a result, participants were unequivocal that there needed to be some kind of directory of diseases setting out the circumstances under which somatic genome editing could be used. This could take the form of something not dissimilar to the National Genomics Test Directory, which the NHS use to determine access to Whole Genome Sequencing provided by the NHS Genomic Medicine Service.[17] It was also felt that such a directory would help mitigate the risk of genome editing being used to 'treat' conditions causing disabilities that are not life-threatening.

Despite the aforementioned optimism, there were lots of questions about the safety of its use in humans and concerns about access to somatic genome editing. It was explained by facilitators and experts that although the genome editing technique CRIPSR/Cas9 is more precise and efficient than other genome editing techniques that preceded it, it is not always understood or known by scientists what effect the introduced edits could have on the function of behaviour of the targeted gene. As a result, there were long discussions about safety and unintentional changes to similar DNA sequences made elsewhere in the genetic code ('off target effects'), and as a result the use of somatic genome editing on humans became unacceptable to participants until the techniques are made safe to use and effective. Concerns about unknown consequences were not just limited to somatic genome editing but related to genome editing overall.

"I'm worried about knock on effects, how much do scientists actually know about what they are doing and when will the effect show up?"
Event 2, Cambridge

Participants were introduced to the idea of gene therapies as a practical example of how somatic genome editing could be used for medical purposes. They were presented with the overall idea that gene therapies

[17] https://www.england.nhs.uk/genomics/nhs-genomic-med-service/

could involve collecting cells from a patient, editing the genome of those cells (such as by repairing or removing malfunctioning genes) and then reintroducing the modified cells back into the patient by a delivery system, such as a blood transfusion. While there was positivity towards genome editing being used in this way to treat medical conditions, there was real concern **that somatic genome editing and gene therapies would increase health inequalities and inequity of access to breakthrough treatments.** This concern stemmed from the view that breakthrough treatments like gene therapies and somatic genome editing for medical purposes would be prohibitively expensive, at least for most of the population initially, and that the effect of this could create a society of 'genetic haves' and 'genetic have-nots'. This fear of inequality was not limited to only the use of somatic genome editing, but on balance it was preferred over germline genome editing in humans, as it was felt to retain individual choice and be safer overall.

After discussing both somatic and germline genome editing (more on this below), it was felt on balance that somatic genome editing for medical purposes was the preferred option as it retained individual choice while mitigating the possible negative consequences associated with germline genome editing such as altering the human gene pool and a slippery slope to eugenics. While somatic genome editing was more acceptable for these participants, provided its effects are safe and can be accurately predicted, there was a sense of resignation that the day would come when somatic genome editing would become commonplace and as a result make it more likely that germline genome editing would one day also become acceptable and commonplace. This was particularly a concern among older dialogue participants.

4.1.2 Views of genome editing plants and crops

Initially most participants felt unsure about the acceptability of genome editing plants and crops because they **saw the process as the same as genetic modification of food, which participants associated as being unnatural and bad for the planet.** There has been controversy around genetically modified crops in the past and some participants in the dialogue held views that these should not be grown, for environmental protection reasons. Genome-edited crops are currently regulated the same way under EU law as genetically modified crops[18].

Participants were not clear at the beginning about the difference between genetic modification, involving introducing foreign genetic material from another organism, and genome editing, which typically involves altering the genes that already exist in an organism. Because of this, participants initially considered both genetically modified food and genome-edited food in the same way and felt that potential perceived risks such as detrimental impact on natural ecosystems outweighed the possible benefits for genome-edited food production.

Once participants learned about the distinction between the two genetic technologies, more participants were supportive of using genome editing technology on plants and crops. **Participants were more supportive of using genome editing to modify genes already existing in an organism than they were of genetic modification. This is because the former could be used to obtain an outcome that might otherwise be achieved through more 'natural' means of selective breeding, albeit much more slowly.**

[18] https://www.theguardian.com/environment/2018/jul/25/gene-editing-is-gm-europes-highest-court-rules

There was concern among participants that the rest of society would not know the distinction between the two technologies (genetic modification and genome editing) and therefore would not be open to learning about the potential benefits of genome-edited crops. As we discuss in the following chapter, it was felt that clarification around this distinction is an important aspect of plant scientists making the case for the use of genome editing in plant and crop science, as well as the commercialisation of genome-edited plants and crops.

Participants felt that genome-edited plants and crops could help to tackle food insecurity in both the developed and developing world, and some felt genome-edited plants and crops would lower food prices, thus helping to tackle the issue of food affordability around the world. They saw genome-edited crops as being a lower-risk option than genetically modified crops for achieving this, as the process was viewed as being more similar to selective breeding.

While cosmetic edits to plants and crops on their own were viewed as having little value other than increasing consumer choice, such changes were felt to be acceptable if they were as a consequence of making food healthier and crops more resilient.

"If you can produce food to feed everybody, whatever way you use to produce it, that's got to be a good thing. That will make the world more equal if we can feed everybody."
Event 2, Cambridge

Participants were also unclear why genome-edited food was subject to the same regulations as genetically modified food under current EU regulations, and so they felt that more research is needed to understand the effect of genome-edited plants and crops on humans and 'natural' ecosystems.

4.1.3 Views of genome editing animals and livestock

Genome editing animals and livestock was initially felt to be less controversial than using the technology on humans, and participants saw potential benefits of using the technology on animals. These included editing out the ability for animals to carry or contract diseases (such as with the mosquitoes that carry malaria) and to enable more sustainable farming (i.e. animals may require less food and care if they are more resilient). Some participants were less comfortable with the use of the technology to increase produce from the farming of livestock, while others saw benefits of this in feeding a growing population.

"Genetically modifying animals so they don't get diseases is good but taking advantage and abusing them for more food is not right."
Event 2, Cambridge

Despite participants seeing benefits of editing the genome of animals, they also had some concerns around this use of genome editing. One of these was animal welfare, specifically worries that genome-edited animals could suffer more – an example participants gave is if genome editing technology allowed chicken farmers to fit more chickens into the same space as non-genome-edited chickens; the genome-edited birds could suffer more due to a lack of space. In reality, there are laws protecting the welfare of livestock[19] that farmers have to adhere to, but should production of genome-edited livestock become commonplace these regulations may need to be reviewed to understand whether the technology impacts them.

Another red flag for participants around this use of genome editing technology was **how eating genome-edited livestock could affect humans**. Participants had discussed potential unintended consequences of genome editing (off-target effects) more broadly earlier in the event, and raised concerns about off target effects in genome-edited livestock that potentially meant eating genome-edited livestock could cause health problems. They wanted to be certain that such meat was safe to consume. Participants also expressed concerns about the effects of genome editing animals on the natural ecosystem.

"How it would affect our health, future, and makeup? There's evidence already that hormones pumped into cattle come into the food chain and cause infertility in young men. If it changes their makeup and we eat it, it will have an effect on us."
Event 2, Cambridge

Editing the genomes of animals, such as pigs, to grow organs that could be successfully transplanted into humans was initially viewed as more controversial than other uses of the technology on animals (for farming livestock). However, **overall many participants came to accept the idea, with some participants believing that this practice happens already**. If proven to be safe, there was a view that successfully transplanting animal organs into humans, a term known as xenotransplantation, using organs grown in a genome-edited animal might gain public acceptance in the future.

4.1.4 Views of heritable editing for medical purposes ('germline genome editing')

For participants, applying germline genome editing in humans was the most controversial potential future use of the technology. They recognised how impactful this technology could be because its heritable nature has potential repercussions for many generations of people. Participants were also clear that, unlike somatic genome editing of humans for medical purposes, germline genome editing alters the genome at an embryonic stage of development, and hence people would not be able to consent to having their genome-edited.

Participants did see some benefits of using the technology in humans though, specifically if used to treat serious diseases that do not have effective treatments or cures such as Huntingdon's. The basis of arguments for the use of this technology in this context was that it should be used to reduce suffering. There was a view that an internationally recognised code should be developed that states which human diseases can and cannot be treated (i.e. which genes can and cannot be edited) with germline genome editing. Some participants thought that using germline genome to treat serious diseases was economically beneficial as it would be cheaper to edit these traits out just once than to treat many generations of patients with the same disease.

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[19] https://www.gov.uk/guidance/animal-welfare

"If there is the potential to prevent children and babies being born with a life altering or limiting disease it is a big positive."
Event 2, Cambridge

Participants felt that for non-life threatening diseases or where appropriate treatments are already available, germline genome editing should be avoided. There were also worries about not being able to anticipate all the effects of germline genome editing humans; there could be unintended consequences which might be detrimental to the person whose genome is edited, and desirable traits could be unwittingly edited out of the germline.

Participants learned about the actions of He Jiankui, who illegally created the first genome-edited babies.[20] It is unknown whether these babies will suffer unintended consequences from having their genomes edited, and this unknown validated participants' concerns about the current use of germline genome editing in humans. They also expressed clear restrictions about rogue scientists like Jiankui being able to use this technology and expressed worries over how this technology is regulated.

4.1.5 Views on heritable genome editing for non-medical purposes

While participants could accept the use of germline genome editing to counter serious diseases in humans, almost all were strongly against the use of the technology for changing aesthetic features such as eye or hair colour, generally referred to as cosmetic uses of genome editing, or for changing features such as eyesight, intelligence or endurance, referred to as human enhancement. Most were concerned about using germline genome editing for these purposes, seeing this as unnecessary and unnatural.

"I've written a red line under hair and eye colour. Intelligence, I don't know. Maybe I'm a bit of a traditionalist. The family looks are passed down. Why would you want to change that?"
Event 2, Cambridge

Similarly, using genome editing to 'improve' humans was also viewed negatively. Participants felt that using genome editing technology to create humans able to thrive in challenging or hazardous environments was not needed as other areas of technology such as robotics could perform these functions. There were also concerns about technology enabling human enhancement falling into the wrong hands of being used for nefarious purposes, such as creating genetically enhanced military forces.

"I know it says on here 'future possibility,' but it really what I see on here is 'future abuse.'...I think this should be off the table."
Event 2, Cambridge

Participants were also concerned that using genome editing technology to enhance human traits could exacerbate divisions in society and create inequalities between those who can/have had their genomes edited and those who cannot/have not, which could lead to prejudices and discrimination. There were also worries

[20] https://www.the-scientist.com/news-opinion/china-sentences-gene-editing-scientist-to-three-years-in-jail-66881

that a less diverse society could arise as a result of this technology which would make it difficult for people who are different to flourish.

"If we start editing genomes and then apply them in an immoral way or don't legislate for fairness and equality, then you would be on the road to eugenics…If there are strict rules and regulations it will be more acceptable."
Event 2, Cambridge

Despite the clear concerns and resistance to the idea of using germline genome editing in humans for enhancement or cosmetic purposes, participants unhappily predicted, and concluded, that genome editing technology would inevitably be used in this way. There were perceptions that acceptability of the use of genome editing technology for these purposes may change over time.

"I sense that now people or most people are opposed to 'designer babies'. Maybe in the future, that will be completely reversed."
Event 2, Cambridge

4.2 Implications for the Babraham Institute

Participants were informed that the Babraham Institute uses genome editing techniques in basic research in laboratories with the aims of better understanding biological processes underpinning healthy ageing. While the Babraham Institute does not and is unlikely to conduct research using genome editing to actualise the future possibilities discussed with participants, other scientists and research organisations may seek to use genome editing techniques in these applied ways. In doing so, these other actors may use or build upon the innovative research that the Babraham Institute initially conducted. There is therefore potential for genome editing techniques to be used in ways outside of the Babraham Institute's control, and in ways that could be unethical or at odds with the Institute's values. A discussion was then held about whether the Babraham Institute should be saying or doing anything to inform the public about how other researchers and scientists might use the technology, particularly if they are using/adapting learning developed by the Institute.

Participants wanted transparency and clarity from the Babraham Institute about the research it does using genome editing, and more widely felt the need for an international regulatory framework that scientists who use the technology are mandated to adhere to. While participants were clear that the Babraham Institute has a duty to inform the public about its research using genome editing techniques, they did not feel that there is necessarily a responsibility for the Institute to say what others are or might do using the technology, as this is outside of its control. However, there was a view that the Babraham Institute is well placed as a centre of expertise to advise governmental bodies on the regulation of the technology.

"I don't think you have to guess what other people will do. I think it's fair for you to say, 'this is what we do, and it can go out to others, who may use it in various ways in theory to improve our lives'. You could have all sorts of ideas as to what might potentially happen, and none of it may be true. It's not in your control."
Event 2, Cambridge

"They [the Babraham Institute] work with the other experts, so they might be able to give advice in general or for the government to put legislation in place, but they are not responsible for it."
Event 2, Cambridge

More detailed views of what the Babraham Institute should be communicating about genome editing technology and how it should be doing this is provided in the following chapter, 'Communication and engagement'.

5 Communication and engagement

A key objective of this public dialogue for the Babraham Institute was to better understand how they and the other research performing organisations in the ORION project should engage with the public about disruptive technologies like genome editing. In the second public dialogue event, a discussion took place about this, in terms of: what messages should the Babraham Institute be communicating to the public, and how should it achieve this? 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' [21] created for the purpose of these public dialogues, in collaboration with artist Emilia Tikka and another ORION partner organisation (MDC, Germany), and were asked to reflect on it.

5.1 Communications context

It is important to note the Babraham Institute already undertakes a broad range of public engagement activities, such as running onsite events for students and teachers, hosting community visits, and participating at science festivals among other activites.[22] The Babraham Institute is also a core partner in the ORION Open Science project which aims at enhancing science and society engagement.[23] Other scientific organisations are also dedicated to engaging with the public about genetic technologies, for example The Royal Society's public dialogue about uses of genetic technologies.[24] The Nuffield Council of Bioethics argues that researchers using genome editing technologies have a responsibility to engage the public and account for public views.[25]

With public concerns about economic inequality, NHS services and provisions, and social division and polarisation among other issues, there is a risk that messages about science and technology could be drowned out. In addition, evidence suggests that a sentiment of populism is eroding public trust in 'experts'[26], but despite this, scientists remain one of the most trusted professions.[27]

The wider context should be borne in mind when considering how to communicate genome editing technology. Genome editing technology also needs careful framing as it is difficult to predict with certainty what impact it will have on society. It should be communicated about in ways which ensure that uses and possible applications are understood by the public, while managing expectations around possible benefits.

5.2 How should organisations like the Babraham Institute engage with the public around genome editing technology?

Participants were optimistic about the potential of genome editing technology to improve treatments, public health and food production. At the same time, many expressed discomfort about the idea of possible negative consequences for society and the planet. As a result, participants called for more communication and

[21] https://www.emiliatikka.com/new-page-1
[22] https://www.babraham.ac.uk/about-us/impact/public
[23] https://www.orion-openscience.eu/about
[24] https://royalsociety.org/~/media/policy/projects/gene-tech/genetic-technologies-public-dialogue-hvm-full-report.pdf
[25] https://nuffieldbioethics.org/wp-content/uploads/Public-Dialogue-on-Genome-Editing-workshop-report.pdf
[26] https://www.ipsos.com/sites/default/files/ct/news/documents/2019-09/populist_and_nativist_sentiment_in_2019_-_global_advisor_report_-_gb.pdf
[27] https://www.ipsos.com/ipsos-mori/en-uk/trust-politicians-falls-sending-them-spiralling-back-bottom-ipsos-mori-veracity-index

engagement with the public, as they wanted to ensure that the public's view could help to inform decisions around the deployment of genome editing technology.

5.2.1 What should organisations like the Babraham Institute be saying to the public about genome editing technology?

As mentioned in section 3.1, at the outset of the event, few participants had heard about genome editing technology and there was little understanding of the different ways it can be applied today and in the future.

Thus, the dialogue participants felt the scientific community should create some form of formal, agreed and respected public-facing documentation about 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 settings beyond research laboratories, could bring wide-ranging benefits which cannot yet be predicted with certainty.

For the purposes of this report, we refer to this hypothetical documentation as a 'roadmap' for the public.

"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

There should also be clear messaging about what is and is not currently allowed regarding the use of genome editing technology, in terms of how scientists are currently able to use it and how they are not currently able to use it (and why they are not allowed to) to provide reassurance around some of the more potentially contentious applications. The public have barriers of what is and is not acceptable around the use of this technology depending on the context; these are 'red lines' that they do not want scientists to cross and want these to be seen to be respected. For example, communicating that research using heritable genome editing in humans is currently illegal in the UK could diminish fears around the technology being used to create 'designer babies'. Given the perceived complexity and number of applications of the technology, the public felt it would be important for communications to address their concerns and questions regarding the principles they hope will guide its deployment, namely: social justice, equity, and fairness.

"Last session I asked if it is policed properly, the expert said yes. It was great to know that they are monitoring it."
Event 2, Cambridge

Controversy and confusion around genetically modified (GM) foods have affected the public's perceptions of genetic technologies in the past. In the dialogue, clear and digestible messaging about the distinction between GM food and genome-edited plants and crops led more participants to support the idea of using genome editing technology on plants and crops. Participants were more supportive of using genome editing to modify genes already existing in an organism to speed up results that could otherwise be achieved through selective breeding than they were of genetic modification where genes are transferred between species (associated with GM foods). In order to ensure the public is as informed as possible, it would be helpful for the public to have clear, simple information explaining what the difference is between GM and genome editing, otherwise members of the public will think these terms are synonymous.

"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

Participants were clear that any information about genome editing presented to the public should be made as accessible as possible using clear and simple language. We suggest that when communicating about the technology, using summaries in layman's terms would be most appropriate; technical terms such as 'somatic' and 'germline' should be avoided in favour of definitions of whether genome editing is heritable or not.

"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

Participants thought more technical information should be available to members of the public who want to view it, which supports the underlying principles of Open Science, but most were sceptical that they would seek this out, instead prioritising the need for the aforementioned roadmap about potential benefits of the technology.

"Scientists will find it hard to use normal words…It is the wording that puts people off."
Event 2, Cambridge

"They need a PR team and someone with a scientific background because you need someone to explain to the scientific press and someone who can put it over in a simpler way…They can convert jargon into something that is transferrable and understandable by the public."
Event 2, Cambridge

One way participants felt could bolster perceptions of transparency is for scientists to communicate about their failures and what has not worked, as well as their successes. This will help to ensure that genome editing technologies are presented in a balanced way and will foster public trust.

"In a balanced way, the negatives as well as the positives. If you constantly put a positive spin on it, you think, 'It's just because they want to make money'. If you give a balanced view, people trust it more. Just be factual and honest."
Event 2, Cambridge

Another way to build trust is to show examples of scientists talking about genome editing from their own perspectives – one way to do this is by getting scientists talking with members of the public at events like this dialogue. Other suggestions from participants included having videos of scientists talking about genome editing or placing pictures and contact details of scientists at the top of articles they have written about genome editing.

"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

Some participants wanted to know about the applications of genome editing technology and others wanted to be able to relate more to scientists by understanding their motives, values, and what drives their research. If scientists communicated about their motives and values, it could help to build trust between society and scientists. Once this is in place, people may be more open to learning about scientists' research using genome editing technology.

Dialogue participants wanted scientists to be open with the public about their research, but at the same time participants were worried the effect of this would be to distract scientists from doing their research. Because of this tension participants came to the view that scientists should be given support and resources to help them be open with the public and to do so in a way that is digestible.

5.2.2 What methods of engagement should organisations like the Babraham Institute use when communicating with the public about genome editing technology?

During the discussion, various methods of engagement about genome editing technology were presented and discussed with participants. They were asked to rank these from their most to least preferred and explain why they chose this ordering. The methods shown to participants were:

- Animated videos
- Videos of scientists talking about their work
- Television
- Academic journals
- The Babraham Institute website
- Social media
- Citizen science
- Citizen's forums
- Printed media
- Public Science fairs
- Exhibitions showing the technology and Open Days

- Theatrical performances

The dialogue participants were very clear that public dialogue or deliberative workshops are highly effective methods of engaging the public in the technical and ethical issues arising from genome editing. They felt the extended sessions ensured there is the time needed to learn about its risks and benefits and then to form opinions about its acceptable and less acceptatable uses. They particularly liked discussing the issues in the presence of experts as they felt it enabled them to become more informed and develop their views. However, participants thought that this method has its limitations because it involves only a small number of people.

"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

"You can't reach a general population [with these public dialogue events]. You want to spread the message far more widely."
Event 2, Cambridge

Participants felt that all of the methods of engagement presented had pros and cons, and that there was no one perfect approach. Therefore, when engaging with the public, a combination of approaches is needed. Overall though, participants prioritised engagement mechanisms they thought had the widest reach. Some of the most popular engagement methods included animated and other videos, including videos of scientists talking about their work. This was because these methods were seen as having potential to reach a lot of people and were easily digestible. Online resources were also ranked highly as they were seen as having a wide reach. This includes social media, which was viewed as a powerful and widespread engagement method. It was felt that these engagement methods that had the widest reach could be used as a 'building block' to pique people's interest, who may then seek out more in-depth information about the technology in other ways.

"Animated video was our top. It was suitable for all ages. Social media, everybody uses social media nowadays. Third was the website. Once people are interested, they will go and check out the website. We had videos of scientists talking [ranked highly]."
Event 2, Cambridge

Table 5.1: Participant's views of pros & cons of each engagement method

Method	Pros	Cons
Animated videos	Can portray complex information in simple ways Visually engaging Suitable for children	Likely to be short and not as in-depth as some other methods

Videos of scientists talking about their work	More personal than other methods Seen as a trustworthy source	Risk of scientists using language that is overly complex or too technical for the public
Television	Has a wide reach	May be expensive to produce and promote a show for television
Academic journals	Seen as a trustworthy source	Not a wide reach - only people with a specific interest would seek these out Not easy for the public to understand
The Babraham Institute website	Viewed as direct and trustworthy	People who are unaware of the Institute are unlikely to go to the website spontaneously
Social media	Inexpensive Has a wide reach	Mentions of 'fake news' and questions over the reliability of what is posted on social media Not a particularly in-depth source of information
Citizen science	Engages and involves the public directly	Low awareness and understanding of this method – would need to be explained Likely to be circumstances where this method is unsuitable, such as when conducting very complex research
Citizen's forums (such as dialogues, juries, and assemblies)	Able to talk to experts, which benefits both the public and the experts Complex information can be understood – enough time is given to talk about the issues Attendees will go out and talk about what they have learned with their friends and family members	Very limited reach Requires a lot of time investment
Printed media	Many people still read printed media May be perceived as more trustworthy than online sources	Viewed as old fashioned
Public Science festivals	Can engage people in fun and interesting ways Can take place in public spaces, such	Not everyone will want to attend these – limited reach

	as shopping malls, to widen reach Detailed information can be provided at these events	
Exhibitions showing the technology and open days	Can engage people in fun and interesting ways Detailed information can be provided at these events Engaging for children	Not everyone will want to attend these – limited reach
Theatrical performances	Makes people think about issues in different or new ways	Perhaps too open to interpretation Can be seen as exclusive

Given that participants felt the impact of the technology could be so transformative to society, they suggested that children should be taught about it in school. The Babraham Institute already conducts educational work with schools, such as open days that pupils can attend – this type of work appears to be valuable to the public and should continue.

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

We recommend that when deciding on the best ways to engage the public around genome editing technology, decisions about the method used are made only once the purpose of the engagement is clearly defined. If the purpose of the engagement is to inform as many people as possible, an online approach could work well. If the purpose is to improve people's knowledge of genome editing technology in depth, an event at a science festival or open-days where the public can meet and talk with scientists could work well. If the purpose of the engagement is to get members of the public to think about the ethical and societal issues surrounding the use of genome editing technology, to make up their own minds and form their own opinions, then an event like this dialogue or art-based methods such as theatre or art pieces could work well.

Overall, participants felt that the Babraham Institute should be prioritising the use of online resources such as animated videos, videos of their scientists talking about its work, and their website, as it was felt these methods would reach the most people. It is worth noting that creating video content and building an audience could require a lot of time and resources from the Babraham Institute. A more efficient solution would be to link in with existing platforms that already have a wide audience with the public, for example YouTube channels dedicated to science promotion or participating in televised documentaries.

5.2.3 Views of using an art piece as a medium for engagement regarding genome editing technology

The ORION consortium wanted to incorporate a piece of art to this public dialogue as a different way of encouraging participants to discuss about a potential future scenario arising from genome editing 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 '*AEON Trajectories of longevity and CRISPR*'. Images of the artwork can be found on Emilia Tikka's website.[28] 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.

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

Figure 5.1: Images of AEON Trajectories of longevity and CRISPR

One of the aims of the art piece was to provoke discussion around the issues arising from a potential future use of genome editing technology. It was successful to an extent at provoking this, as participants were able to talk about their reflections on the art – discussing the issues it was portraying and explain how it made them think and feel. Some participants recognised that the art piece was meant to make them question how the technology might be used in the future. It made them think and feel differently about genome editing technology and as as a result they were less optimistic about the technology than they had previously been.

"That's not living. You're not enjoying anything. You're not eating dinner. You're having water. You're watching your loved ones die. I feel so sad."
Event 2, Cambridge

It was also clear to participants that their perceptions were being influenced by the artistic choices made by the artist in the design of the piece, with participants referencing the use of black and dark colours, showing the male figure as needing to wear a facemask and consuming tablets rather than a full meal. Participants stated that if the artist had decided to depict the technology differently, for example with bright colours, sunny images and less sombre scenes, the piece would make them feel differently.

"It is subject to the artist's interpretation and then your interpretation about her depiction."
Event 2, Cambridge

Participants found the accompanying information presented to them about the art piece helpful to understand it and engage with the issues it was portraying (this was a single slide of information shown on a projector in the room throughout the discussion about the art piece. The slide can be found in Appendix E). Without this information, it would have been difficult for participants to understand the ethical issues being depicted.

Some participants misinterpreted the intention of the piece as trying to promote the use of the technology and felt if this was the case it was not an appropriate way of doing this – because viewers felt that it depicts the technology in a negative way with a bleak outlook. Had the artist been able to attend the event she may have been able to further clarify the intentions behind the piece as to reduce misinterpretation; unfortunately, this was not possible due to practical constraints.

"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

There was also a perception that art, such as this piece, is likely to appeal to certain groups of people more than others. For example, attendance to galleries has been found to differ by socio-economic group.[29] Participants had concerns that the medium would mean some groups are unwittingly excluded.

[29] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/832874/Taking_Part_Survey_Adult_Report_2018_19.pdf

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

Art pieces like *ÆON* are effective in engaging people to an extent and getting them to think about issues and form their own opinions, but there are some caveats. Firstly, the audience should be able to understand the issues the art is depicting, so having written information alongside the art itself is useful (or alternatively having the artist present during its exhibition to talk about the work). Secondly, this medium will not appeal to all parts of society.

6 Conclusions & Recommendations

The table below outlines our conclusions drawn from the public dialogue events in Cambridge and considering these, we set out recommendations for the Babraham Institute and the ORION partnership.

Table 6.1: Table of conclusions & recommendations

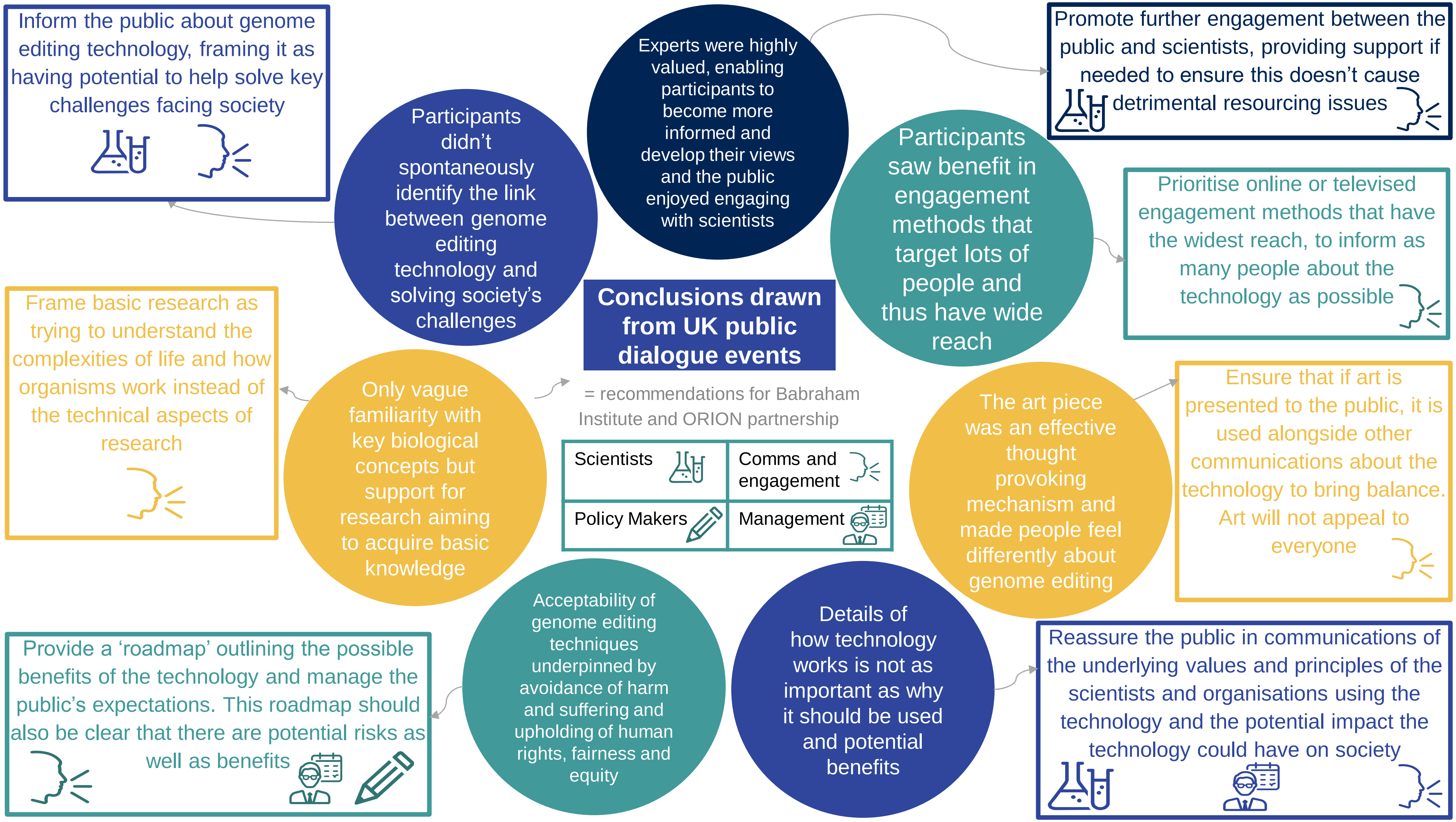
	Conclusions	Recommendations	Recommendation for:
1	Though participants did not initially think of genome editing technology as helping to solve societal challenges, once discussed, they recognised that the technology does have the potential to solve many of them.	Inform the public about genome editing technology, framing it as having potential to help to solve key challenges facing society.	• Communication and Engagement specialists should help to inform the public about the technology • Scientists are trusted figures and will be important in communicating about the technology and its potential benefits/risks
2	There was unanimous support for research for the purpose of acquiring fundamental knowledge, but in general there is, at best, a vague familiarity with key biological concepts.	Frame basic research as trying to understand the complexities of life and how living organisms work, as it will resonate with the public more than technical aspects of the research (such as how proteins work).	• Communication and Engagement specialists – framing basic research in this way could help engage the public
3	The public acceptability of the use of genome editing technology is underpinned by avoiding harm and suffering, and protecting social justice, human rights, fairness and equity. Participants were positive about the possible benefits of the technology but	Provide a 'roadmap' outlining the possible benefits of the technology and manage the public's expectations by stating this is currently a novel and somewhat unpredictable technology. This roadmap should also be clear that there are potential risks as well as benefits, which is why the technology is currently being conducted in	• Communication and Engagement specialists, Management within the ORION partners, and Policy Makers would ideally all be involved in the development of this roadmap

	were not willing to let it infringe on these principles.	laboratories in basic research before it can be used in applied situations. Rules and governance over the technology need to ensure that these principles are not undermined by its use.	
4	Participants felt that the technology was complex and technical and were more interested in understanding about why this technology should be used and what benefits it is hoped will be achieved from using it.	Reassure the public in your communications of the underlying motivations why the technology is being used at the organisation and the potential impact the technology could have on society, in order to create trust with the public.	• Scientists should be clear about their motivations for using the technology to bolster public trust • Communication and Engagement specialists should provide support where needed to scientists to be able to do this • Management within the ORION partners should give the Communication and Engagement specialists the resources needed to support scientists in this way, such as ensuring they have enough time or staff to conduct training sessions or provide guidance
5	The art piece was an effective mechanism for provoking thought and debate. Participants interpreted it as predicting a bleak, negative future caused by the technology. Some participants saw it as a promotional piece (albeit not a very successful	Ensure that if art is presented to the public, it is used alongside other communications and messaging about the technology. Doing so will help to bring balance to how the pros and cons of the technology are presented, and because the medium of art will not appeal to everyone.	• Communication and Engagement specialists should consider using different communication methods alongside art

	one), though this was not the purpose of it.		
6	Given the potentially large impact the technology could have for society, participants thought that organisations like the Babraham Institute should be using engagement methods that will reach the largest proportions of the public.	Prioritise online or televised engagement methods that have the widest reach, to inform as many people about the technology as possible.	• Communication and Engagement specialists should consider online or televised approaches to engage the public about genome editing
7	Participants really valued having experts at the events , they felt it fostered trust, and liked the idea of being able to engage with scientists. Public engagement methods that put scientists who use the technology at the forefront, such as videos of scientists talking about their work, were ranked highly by participants.	Promote further engagement between the public and scientists, and personalise communications about genome editing technology where appropriate to come from individual scientists. Provide support to scientists to ensure they are able to communicate clearly about their work without this causing detrimental resource implications.	• Scientists should be open to interacting with the public about their research • Communication and Engagement specialists might need to provide support to scientists to be able to do this effectively

We have also translated these conclusions and recommendations into a diagrammatic format, which is presented below.

Figure 6.2: Diagram of conclusions & recommendations



Appendix A: List of stakeholders who attended the stakeholder workshop

The table below shows a list of attendees to the stakeholder workshop who have agreed for their names and roles to be listed in this report.

Table 6.2: Names, roles & organisations of stakeholder workshop attendees

Stakeholder name	Organisation	Role
Anthony Whitney	Department for Business, Energy and Industrial Strategy	Senior Policy Advisor
Dave Hughes	Syngenta	Head of Technology, Identification and Evaluation
Rumiana Yotova	Faculty of Law, University of Cambridge	Lecturer and Director of Studies in Law
Helen Ferrier	National Farmers Union	Chief Science & Regulatory Affairs Adviser
Phillipa Brice	PHG Foundation, University of Cambridge	External Affairs Director
Tanya Bridgen	PHG Foundation, University of Cambridge	Policy Analyst
Carine Stapel	The Babraham Institute	Marie Curie Postdoc Fellow, Dr Wolf Reik group, Epigenetics research programme
Katharina Boroviak	Wellcome Genome Campus	Senior Staff Scientist

Appendix B: List of experts who attended the events

The table below shows a list of experts at the public dialogue events.

Table 6.3: Names, roles & organisations of experts who attended the public dialogue events

Stakeholder name	Organisation	Role
Event 1		
Carine Stapel	The Babraham Institute	Marie Curie Postdoc Fellow, Dr Wolf Reik group, Epigenetics research programme
Dave Hughes	Syngenta	Head of Technology, Identification and Evaluation
Amarpreet Kaur	University of Cambridge, Department of Sociology	PhD student
Event 2		
Carine Stapel	The Babraham Institute	Marie Curie Postdoc Fellow, Dr Wolf Reik group, Epigenetics research programme
Jasmin Taubenschmid-Stowers	The Babraham Institute	EMBO Postdoc Fellow, Dr Wolf Reik group, Babraham Institute's Epigenetics research programme
Peter Rugg-Gunn	The Babraham Institute	Group Leader, Epigenetics research programme
Helen Anne Curry	University of Cambridge, Department of History and Philosophy of Science	Senior Lecturer

Appendix C: Case Studies shown to participants

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.

Ipsos MORI
Social Research Institute

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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.

Ipsos MORI
Social Research Institute

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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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Social Research Institute

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Appendix D: 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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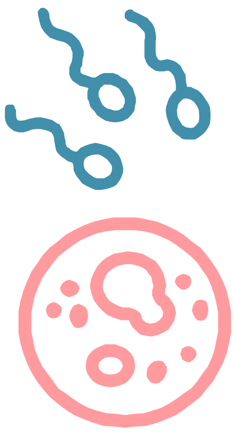
Future possibility 1: Genome editing human embryos

- 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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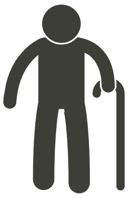
Future possibility 2: Changing traits in humans

- 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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Social Research Institute

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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

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Appendix E: 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 F: 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 similarilty 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 G: Advisory Group & Review 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[30]	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)

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

UK Review Group members

Name	Organisation	Role
Michael Wakelam[30]	The Babraham Institute	Director
Wolf Reik	The Babraham Institute	Head of the Epigenetics Programme
Sarah Ross	The Babraham Institute	Immunology Programme Principle Investigator
Louisa Wood	The Babraham Institute	Communications Manager
Stephanie Norwood	The Babraham Institute	Public Engagement ORION Project Officer (maternity cover)
Sarah Miles	The Biotechnology and Biological Sciences Research Council (BBSRC)	Stakeholder Engagement Manager
Anthony Whitney	Department of Business Energy and Industrial Strategy, UK Government	Head of Public Engagement with Research

Appendix H: 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[31]	The Babraham Institute	Public Engagement ORION Open Science Project Officer (maternity cover)
Tacita Croucher	The Babraham Institute	Public Engagement Manager
Hayley McCulloch[31]	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[31]	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

[31] 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.