# Public dialogue on genome editing

## Sweden country report

**By VA for the ORION Open Science project**

**March 2021**

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 741527.

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# Acknowledgements

The international public dialogues were funded by the ORION Open Science project[1], with the UK ORION partner, the Babraham Institute, acting as the lead organisation.[2] The authors of the report would like to thank the staff in the Public Engagement Team at the Babraham Institute for their support, as well as members of the international Advisory Group and Review Groups who reviewed drafts of the materials used in the public dialogue events and the reporting outputs from the public dialogue. We also thank the team members at Ipsos Germany and Ipsos Czech for their role in organising and delivering the events in their countries.

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 Swedish 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 the Advisory Group and Swedish Review Group who have agreed to be named in this report are listed in Appendix G. The Ipsos project team who contributed to this project 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 institutions are located; the UK, Germany, Sweden and the Czech Republic. **This report details findings from the dialogue held in Stockholm (Sweden), which was led by Vetenskap & Allmänhet (VA, Public & Science).** During the events, members of the public discussed applications of genome editing techniques, possible future uses of the technology, and explored the best ways for the ORION partners to engage with the public about genome editing.

## Views on key societal challenges and solutions

Participants were invited to think about key challenges and problems currently facing society and how those challenges could be solved. **The key challenges identified related to climate change, health, crime and security, as well as economics.** While none of the participants mentioned genome editing technology as a solution to these problems, **they did propose solutions that genome editing technology might help to deliver**. Funding research to find solutions to problems was seen as a positive approach. Technological solutions that do not currently exist were also discussed as potential solutions for the future.

## Views of basic research and genome editing techniques

**Participants overall had good knowledge of key biological** concepts such as DNA, genes, cells and **were positive towards genome editing being used in basic research.**[5] Participants saw research as a way of generating solutions for societal problems. There were a few caveats/concerns raised about how research is conducted: who is funding the research, and whether this would bias the results depending on whether it was being funded by private companies, and the cost of research. There were also concerns about knock-on effects in nature, the potential for exploitation and differential access, the kind of waste generated from this kind of technology and the associated ethical issues (regarding embryonic research). Additionally, participants were surprised to hear (from experts) that current genome editing technology as it stands today is only useful in a limited number of diseases that were very well defined and known to be caused by a single gene.

## Views of possible future uses of genome editing

Participants discussed a range of future possible uses of genome editing applications. **There was consensus from participants that somatic genome editing[6] was acceptable** when tackling life threatening illnesses and

[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.

when treatment was likely to have a high chance of success. Participants could not easily see the benefits of genome editing in plants and crops and had mixed views on editing the genomes of animals and livestock. There was less positivity towards germline genome editing[7] and participants were unsupportive of the use of technology for human enhancement or changing cosmetic traits. Regarding germline genome editing, there were concerns about the creation of a superior race, the permanence of the change, and therefore raised risk.

### Communication and engagement

**Transparency is key when it comes to communication with the public.** Participants of the dialogue didn't just want to know the end result of research, they wanted to know the details; how research had been done and who was funding it. The represents a challenge for the ORION partners. Research findings published in popular press tend to be short and concise summaries of results or applications of research, with little room for expansion or nuance. ORION partners must find was to communicate with the public so that they can easily access all the information they need to make informed opinions. Participants were surprised about how much they learned at the public dialogue and how important the discussions were. They were also surprised that these issues were not debated or publicised more in the popular press. **ORION partners need to find ways to present the important information to the public via media that they already use to get information.**

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

**Participants were happy to be involved in the public dialogue**, expressing that it was good to learn about genome editing technology and have their opinions heard. **However, they also realised that public dialogues are not the most effective way to communicate with many people** and therefore suggested supplementing engagement by using **TV adverts, Netflix documentaries, advertisements in the metro and on social media**.

Participants were shown an art piece – *ÆON*[8] – depicting a hypothetical future scenario where genome editing technology is used to preserve youth. **The art piece was very effective at stimulating discussion around genome editing.** Ironically, even when participants stated that it didn't help, this led to discussion. The art piece was very good at drawing out opinions. The piece stimulated discussion, but in the context of the public dialogue where participants had access to a lot of extra information. This may be particularly true of the events in Sweden where participants had an opportunity to see the art piece before the events and were able to hear from the artist during the first event. **Despite some negative sentiment, participants accepted that art does matter and is a good communication medium, providing people have time to see and think about it properly.**

### Key conclusions

Participants could see the value in conducting basic research but had concerns around how the research itself is conducted and the effects this could have on the environment. In terms of future uses, there was most excitement about the potential of somatic genome editing in tackling life threatening diseases. Participants felt transparency was very important when it came to communicating with the public about the technology and that it is important to consider channels that will reach many people.

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

[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) Work 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 behavioral 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 Centers, 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 center of scientific excellence combining life sciences, advanced materials and nanotechnologies.

**Vetenskap & Allmänhet** (VA, Public & Science), 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 Sweden.** 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 Sweden 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. A list of Advisory Group members who have agreed to be named in this report can be found in Appendix G.

### 1.3.1 Governance

International Advisory Group:

An international Advisory Group was convened to provide oversight and governance of the overall project. The Advisory Group membership consisted of international stakeholders with knowledge and expertise in genome editing, the ethical issues associated with the technology, and science communication as well as senior management from each of the four ORION partners involved in the project.

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 Swedish Review Group membership consisted of two members of staff from within VA.

VA & Ipsos MORI

Staff at VA in Stockholm were responsible for arranging and moderating the stakeholder workshop and public dialogue events in Sweden, including analysing and reporting findings from these. Ipsos Sweden carried out the recruitment of participants for the public dialogue events. VA and Ipsos Sweden worked directly with Ipsos MORI in the UK who were managing the overall project in conjunction with the Babraham Institute, the ORION partner in the UK.

VA staff:

VA staff also provided examples of research conducted in Sweden by scientific laboratories using genome editing techniques, serving as the basis of the case studies used in the public dialogue events.

The International Advisory Group, Review Group and members of the Babraham Institute (the UK ORION partner) were involved in reviewing the following elements within the project:

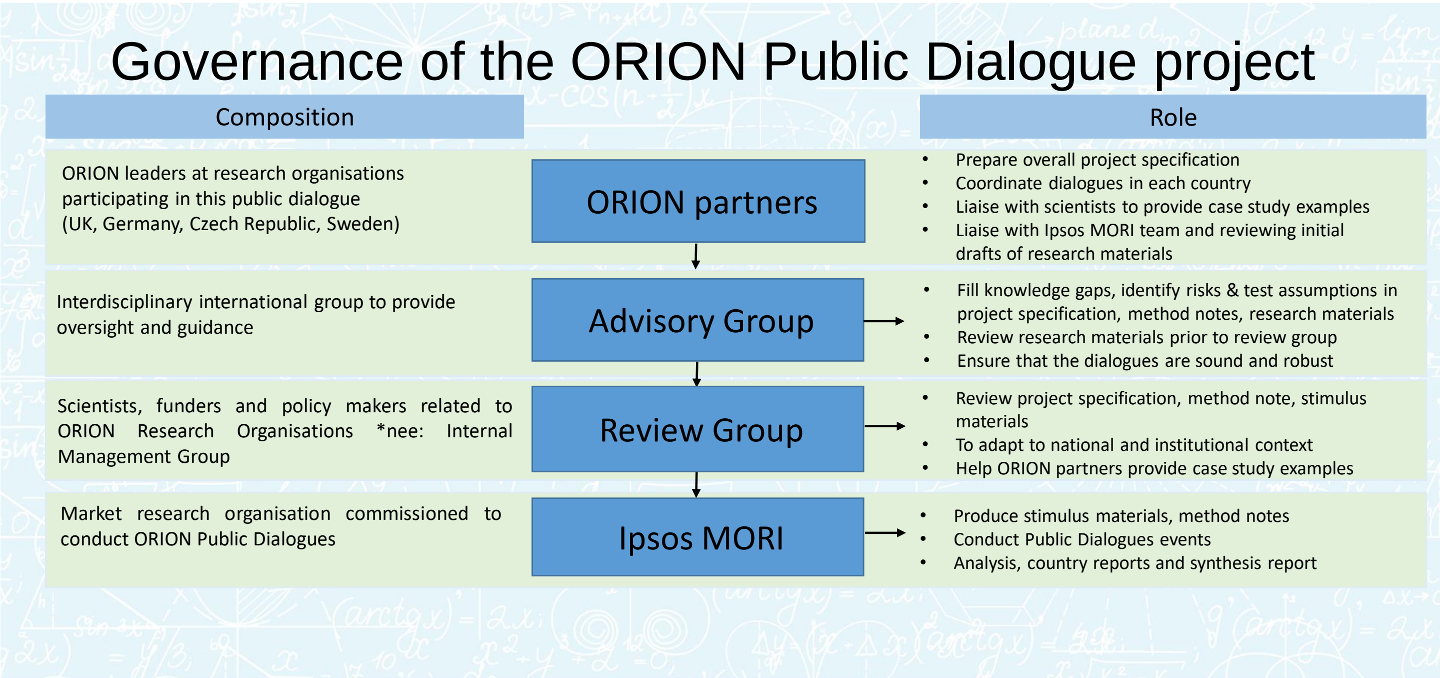
- Project specification – Initial document produced by the ORION consortium that outlined the background, context and rationale behind the project, the aims, objectives and proposed methods, the expected outputs and outcomes, anticipated risks, and proposed method of disseminating findings. It also outlined 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 hand-outs for participants providing examples of how genome editing techniques are currently used by Swedish researchers.

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 ORION partners to develop the materials to use at a workshop with stakeholders in each of the four countries.

3. A workshop was held at the Swedish Research council with stakeholders including experts in genome editing, research funders and policy-makers.

4. Findings from the stakeholder workshops were used to help develop materials for the public dialogues. For the events in the Sweden, VA provided three examples of Swedish 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.

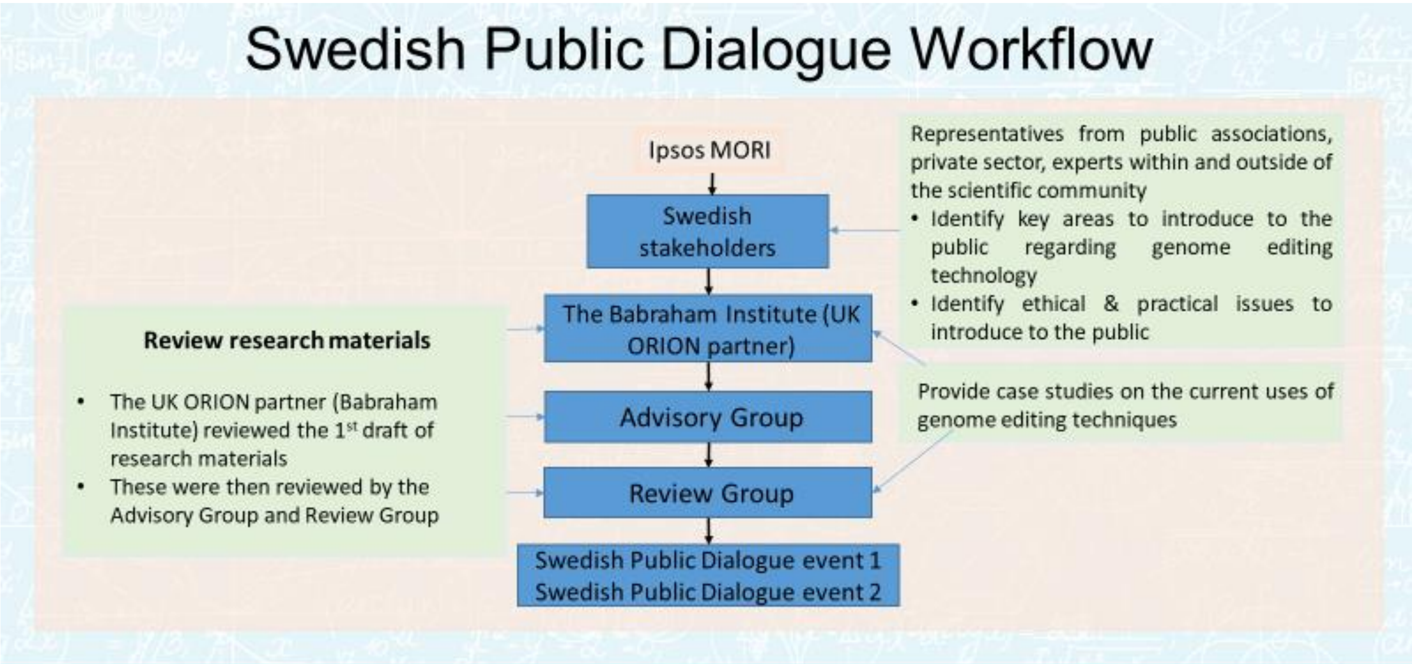
6. A pair of public dialogue events were held with members of the public in Stockholm.

7. Findings from these events were written up into a report and reviewed 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 the Swedish Public Dialogues**




### 1.3.3 Stakeholder workshop

A workshop was held on October 2nd 2019 at the Swedish Research Council, Stockholm, Sweden, with 15 of VA's internal and external stakeholders (i.e. people with a vested interest in genome editing technology, some working at CEITEC and others working for other organisations). The purpose of this stakeholder workshop was to provide insight into the design of the materials to be shown during the public dialogue events. Participants were identified by ORION staff at VA and included a range of experts who bring a perspective on the technical and ethical issues associated with genome editing. These included scientists using genome editing techniques but also other experts who could express 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 Swedish stakeholder workshop**

| Stakeholder Type | Stakeholder Sub-type | No. Stakeholders |
|---|---|---|
| Funders | National funding agency | 1 |
| Industry representatives | Life Science Organisations | 3 |
| Policy makers | Government Offices | 3 |
| Experts in Life Sciences | Researchers | 3 |
| Experts outside of Life Sciences | Non-Government Organisations | 2 |
| | Researchers | 3 |
| Total number of Stakeholders: 15 | | |

### 1.3.4 Public Dialogue events

Two dialogue events were held in Sweden with members of the public to discuss genome editing technology. Both took place at the National Museum of Science and Technology in Stockholm, Sweden. 31 members of the public took part in both events.

Recruitment of participants to the events was undertaken by Ipsos Sweden. In order to recruit participants, Ipsos MORI developed recruitment materials which Ipsos Sweden 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 and a screening questionnaire which collected information about participant characteristics.

Recruitment was conducted online in Sweden. The screening questionnaire was scripted into an online version by Ipsos Sweden and was advertised online via social media as well as being sent to Ipsos Sweden's online panel (a list of members of the public who have signed up as being interested in participating in research). Data was collected online from potential participants, resulting in a large number of people indicating their interest in taking part. Ipsos Sweden were then able to examine the data and choose a pool of participants from those who had indicated they were interested. This pool was determined by quotas set on demographic factors that had been collected in the screening questionnaire such as participants' gender, age, migration status, 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.

Once participants had been selected from those who had indicated an interest in taking part online, Ipsos Sweden conducted follow-up telephone calls with participants to collect additional information where necessary, provide additional information about the public dialogue events and confirm participation. At this stage, participants were also sent a privacy policy outlining who Ipsos and VA 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.

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

| | | |
|---|---|---|
| Location | Urban location | 15 |
| | Suburban location | 16 |
| Gender | Male | 16 |
| | Female | 15 |
| Age groups | 18-30 | 5 |
| | 31-44 | 10 |
| | 45-64 | 10 |
| | 65+ | 6 |
| Country of origin | Sweden | 25 |
| | Other[11] | 6 |
| Child status | Children at home | 10 |
| | Children sometimes at home | 3 |
| | Children have left home | 6 |
| | No children | 12 |
| Employment status | Employed | 19 |
| | Unemployed | 12 |
| Attitudes to genome editing before attending the events | Comfortable with the concept | 10 |
| | Uncomfortable with the concept | 20 |
| | Don't know | 1 |
| | | Total number of Participants: 31 |

[11] Please note that in UK and Czech Republic participants were asked what their ethnicity is whereas in Germany and Sweden participants were asked about their migration background (i.e. where they or their parents were born).

Participants were split into three discussion tables per event, with a good mix of 10/11 participants sitting on each table. 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 scientists identified by the ORION staff at VA. Three experts attended the first event, and three 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 23rd of January 2020. The focus of this event was to give participants the minimum amount of information needed to engage in discussions about the use of genome editing techniques and the issues arising from it. Participants were informed about key biological concepts including DNA, gene, the genome, and proteins, this enabled 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 examples of Swedish research using genome editing techniques. These case study examples of genome editing techniques reflected research undertaken by scientific researchers in Sweden but unlike the other countries did not reflect work conducted by the ORION partner (VA) itself – this is because VA is a specialist in science communication and does not carry out research using genome editing techniques itself.

Near the beginning of the first event in Sweden, Emilia Tikka briefly introduced her artwork *ÆON*[12] to participants, which depicts a far-off speculative future scenario whereby genome editing technology can be used to slow or even reverse ageing in humans. Emilia introduced the artwork and spoke briefly about the associated societal impacts of such a technology. Emilia's talk at this event marks a difference to the events in the other countries as Emilia could not attend the events in the UK, Germany and Czech Republic in person. The art was re-introduced during the second event when it was discussed by participants in detail.

Event 2: The second event was a day-long workshop running between 10am and 4pm on Saturday 8th February 2020. During this event, case studies outlining examples of the Swedish genome editing research were re-introduced to remind the participants about the type of research done in Sweden, this was followed by a discussion of possible future uses of the technology. The afternoon involved discussion of how best to

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

communicate and engage the public around genome editing technology. Part of this conversation involved capturing views on an artwork, specially commissioned for the dialogue, depicting a hypothetical far off scenario where genome editing technology has enabled the slowing down of the ageing process.

Post-event analysis: With participants' consent, discussions at the events were recorded and notes were taken. This information was used in a thematic analysis of the events, which enabled key themes to be developed. These themes 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 dialogue 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,
  - experts were chosen to demonstrate a range of perspectives on genome editing; they did not work for VA 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 incentives being administered after the events via bank transfer, and these came from the organisation who had recruited participants (Ipsos Sweden rather than VA). 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

There were a number of key themes among the challenges raised by the participants. The first was climate. People were concerned that we are seeing the effects of climate change today and the problem seems to be getting worse. Views were related both to evidence from climate scientists and social pressures from movements like the "Climate Strike" which are popular in Sweden.

Health was also raised as a key challenge for society today. Aging populations and the prevalence of hereditary diseases were discussed as well as development and access to medicines. Environmental factors related to health were also raised such as the rise of obesity linked to a sedentary lifestyle and pollution causing health problems. Infectious diseases were also raised as a health-related challenge. Participants were concerned about the spread of global pandemics in the future and how these would be controlled or even eliminated.

Digital security concerns were also raised, for example, the prospect of information about people being available in an easily accessible digital format represents a challenge both now and for the future. Security of personal data as well as clear regulations around who owns the data need to be addressed. Crime and societal cohesion (meaning less factious divides between socioeconomic and ethnic groups) were also discussed as challenges for the future.

Economics was also discussed from two different angles; how will funds be allocated to solve global problems and develop new treatments for disease, as well as who will be able to afford access and benefit from these new treatments.

## 2.2 Spontaneous views of solutions

Economic solutions were discussed extensively. Funding research to find solutions to problems was suggested and generally seen as a positive approach, although it was also noted that sources of funding can also dictate the direction of research in negative ways, for example a particular industry could fund research that is likely to deliver a positive outcome for them. Funding the proper distribution of medicines was also discussed, meaning ensuring that the right people had access to the right medicines when they needed it. There was concern that only the rich would have access to solutions and this was not fair.

Filling any knowledge gaps with education was also seen as a viable solution. Adult education was discussed and the responsibility of governments to make sure good information and education is available to the citizens of a country. School level education was also discussed where participants explained how curricula in schools should be up to date and help society to combat these problems.

Technology was a third solution discussed by the groups. Technological solutions that do not currently exist could be solutions for the future. For example, if food were replaced by a pill, this could solve many health issues from obesity to malnutrition. Although, negative effects of technology were also discussed – the mobile phone was used as an example of technology that is very useful and "good" in many respects, but also has negative effects.

***"If the food is removed and replaced by a pill, I would not feel good psychologically, but as an emergency solution, yes."***
*Event 1, Stockholm*

***"Everyone sits and looks at their phones today. Is it good or bad? Some [contexts] are good, others bad. Mobile phones are a way to spread information."***
*Event 1, Stockholm*

# 3 Views of basic research and genome editing techniques

Prior to the public dialogue event in Stockholm, VA conducted a workshop with their stakeholders with expertise in genome editing from various backgrounds (bringing scientific, ethical, 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 in Sweden 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 Swedish research involving genome editing technology.

## 3.1 Participants' starting points

The participants had a good starting point with respect to biology with most people giving correct responses to the quiz. There were two more complex issues that required further discussion as the conversations continued.

The first was the distinction between genetically modified organisms and genome-edited organisms. The former technology involves introducing foreign genetic material from another organism. The latter technology typically alters the genes that already exist in an organism. This distinction was unclear for a number of participants but was easily grasped after a brief discussion and some explanation from the experts present. The second misunderstanding was the limitations of current genome editing technology as it stands today and in the future. Our experts needed to explain that genome editing technology was only useful today in a limited number of diseases that were very well defined and known to be caused by a single gene. More complex disorders would not automatically be treatable currently using this technology.

## 3.2 Views of basic research using genome editing technology

It was outlined to participants that many scientists such as some of those working for ORION partner organisations conduct early-stage, basic research aiming at understanding fundamental biological processes, which may or may not eventually lead to practical applications. This form of basic research was widely viewed as being positive and necessary. Participants saw research as a way of generating solutions for societal problems. There was no strong negative sentiment about basic research however there were a few caveats/concerns that were raised about how research is conducted.

Firstly, participants wanted to know who is funding the research, and would they bias the results? If private foundations or companies are funding research perhaps, they will skew results or seek to profit from the research instead of helping society.

Secondly, the price of doing research was also raised. While it was seen as a valuable investment, participants acknowledged that it was expensive and perhaps not all research should be funded when the money could be used to help society in other ways.

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

Participants were then shown four examples of Swedish 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: Genetically modified potatoes –** this case study discussed how genome editing provides a faster way to edit crops, to study them or improve them by making them more nutritious or resistant to pests and extreme weather. The case covers how genome editing has now been successfully implemented in research with potatoes, producing new starch qualities for improved usability in food and technical products as well as a low-glycemic index potato i.e. a potato with reduced sugar content.

**Case study 2: Genome editing bacteria to produce biofuels** – this case study covers how scientists are working on genetically modifying bacteria to directly produce biofuels from only light and carbon dioxide.

**Case study 3: Understanding how cells function** – this case study focuses on how genome editing can be used to speed up complex screening processes in research. Using the CRISPR/Cas9 genome editing technique and cells grown in the lab, it is possible to edit many genes at the same time, and then test what effects these edits have on the cells. Scientists are developing a CRISPR/Cas9 screening platform that they can use to study diseases such as cancer and arthritis. They are interested in finding which genes cause disease when they are changed, to then develop better drugs and treatments.

**Case study 4: Editing embryonic stem cells** – age-macular degeneration is the leading cause of severe, permanent vision loss in people over age 60. The final case study discusses how scientists are using the CRISPR/Cas9 genome editing technique to produce stem cells that won't cause an immune reaction and can therefore be used to treat macular degeneration.

### 3.2.1 Case study 1: Genetically modified potatoes

Many participants were quite **neutral** to this case study at first, having no strong reaction either way, the consensus was that they saw no reason not to try it. When the discussion expanded, people saw the benefit of being able to modify crops to produce **more nutritious food**, especially in developing countries. Some participants commented that it would also be beneficial to be able to **grow more exotic crops locally** by modifying them to grow in a colder climate. Participants also thought that it was worth exploring genome editing crops to **produce materials for uses other than food**. For example, if potatoes could be modified to produce more starch, this could be used make biodegradable bags and replace plastic.

Potential concerns were raised about knock-on effects in nature. If the edited crops were free to grow in nature, then they could have unexpected consequences on natural populations of plants and animals. Participants also raised the possibility that if developed countries create new, nutritious crops that are needed in the developing world, the potential for exploitation would be high. If developing countries relied on companies with patents on their food, then their future food security could be in jeopardy.

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

### 3.2.2 Case study 2: Genome editing bacteria to produce biofuels

Participants immediately saw the benefit in this case study to reduce fuel costs. Many people saw this an excellent use of microbes. One participant commented that it was easier to come to terms with this case study as the genetically edited elements would directly affect humans as either treatments or food.

There was debate over whether this was a good investment or not. Some people saw that this was an important line of research as it could have a significant positive impact on the environment with minimal risk. However, some participants questioned whether money spent on projects like this could be better spent to benefit society in a different way, though no explicit examples of other ways of benefitting society were given. People were also unsure about what kind of waste would be generated from this kind of technology. On the surface it seems like minimal waste would be produced but the fact that this was unknown bothered several participants who said they would need to know more details before they could agree to this. Finally, participants were worried about the genome-edited bacteria being released in the wild and causing unexpected effects for the environment or human health.

***"How much does it cost? What is the cost and benefits? Spontaneously – this makes more sense than gene edited potatoes. In our part of the world, biofuels would benefit many people and make a positive change."***
*Event 1, Stockholm*

### 3.2.3 Case study 3: Understanding how cells function

Many participants were positive about this case study, saying that research into diseases is important. Some participants did not even see the need to discuss this case study indicating that it was standard research and should simply continue. They stated that understanding disease is important.

However, there was a consensus that some diseases should be prioritised. The deadlier a disease, the higher priority it should be. People were less comfortable using this as a method for researching minor ailments or diseases with already well-developed cures. The point was also raised about who would reap the rewards of this research. People were concerned that these benefits would be seen by wealthy countries and not by developing countries. There was also concerns over data protection during screening – what data would be given up by participants and who would ultimately be able to access it?

***"People suffer. It is a good idea to cure disease, but who has access to it?"***
*Event 1, Stockholm*

### 3.2.4 Case study 4: Editing embryonic stem cells

This was the most divisive case study; many people thought the potential benefits were life changing and could impact a lot of people. There was nobody who questioned whether the proposed benefits of this technology were positive, the main question was whether they were worth the cost. Some participants were able to draw clear ethical limits saying that this was like organ donation, though these limits varied from person to person. For example, some participants were happy for the use of embryos that were left over from IVF being used in this way.

However, others felt uncomfortable with using embryos from abortions. There was a concern that if this became common place, then there would be a demand and therefore a market for human embryos which was ethically difficult to accept. Some participants also rejected the idea that this was like organ donation as these embryos cannot give prior consent.

***"I think this is great, it's such a waste to throw away embryos left over from IVF."***
*Event 1, Stockholm*

## 3.3 Views of different groups and how they differ

The discussions and conclusions from the different tables were very similar, especially around the more ethically polarising case studies around research and embryonal stem cells. There were no noticeable differences in views by demographic characteristics such as age or gender.

The noticeable differences between each of the discussion tables largely related to two of the examples of research given specifically – the genetically modified food and fuel cell case studies. Here, there were differences depending on starting points of the discussion rather than by characteristics of participants. For example, one table started talking about economics early on and this became a stronger theme in the discussion. Other tables talked about data protection and privacy and this became a bigger feature of the discussion for this table.

## 3.4 Implications for the ORION partnership

It would be easy to think that the public are far more interested in the applications of research rather than the research itself. These discussions indicate that the public are also very interested in research, especially when it comes to ethically charged questions such as those related to genome editing.

Communication around research tends to focus heavily on the results and applications of research, however, this dialogue has shown that communication around the research itself would be useful for the public, as well as ORION partners like VA who specialise in communicating science to the public.

The dialogue also shows that the public can have mixed reactions to many different kinds of research. These reactions will likely dictate the future feasibility of a new technology or at least outline the communication task necessary to facilitate adoption. These options are typically not heard in the types of one-way communication that universities typically engage in. A good example would be the case study concerning microbially produced biofuel. On the face of it, this is a positive innovation that could reduce the cost of biofuel. However, by engaging in two-way communication with the public, it was possible to understand some of the concerns and objections that may be encountered when trying to make put this research into practice. With this in mind, **ORION partners should try to facilitate deeper, two-way communication about their research to understand if their technology has a chance of being adopted in the future.**

# 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 around 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[13], 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 Sweden. 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.[14]
- Genome editing for **human traits** – the idea that in the far-off 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.

[13] https://www.discovermagazine.com/health/gene-therapies-make-it-to-clinical-trials
[14] 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. The case studies were provided to VA to use in the events. 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.

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 ORION partnership.

## 4.1 Overall acceptability of different uses of genome editing

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

**During the discussions there were often examples of somatic genome editing where there was consensus across participants in the dialogue that this editing was acceptable.** For example, it was considered acceptable if a patient had a life-threatening illness and decided themselves to undergo a well-studied therapy based on a genome editing technique that had a high chance of success. There were also scenarios where there was consensus that somatic genome editing was not acceptable such as someone (the state, medical personnel or parents) forcing another person to undergo treatment to cure a non-life-threatening condition. A typical example used was children with Down syndrome. While most people agreed on the extremes, it was difficult for any one participant to decide where the limit of acceptability was. While it may not be possible in practice to treat conditions like Down syndrome using genome editing, at least today, the purpose of this discussion was to understand these limits of acceptability.

***"It is so hard to determine where the limit goes. We might start with epilepsy, then it becomes Down syndrome and soon we're talking about race. It will happen if we unleash this monster."***
*Event 2, Stockholm*

**There was a lot of discussion around the level of certainty involved in a genome editing treatment.** The experts at the various tables explained that a few diseases could be cured with a high degree of certainty, but many others could not be cured until more research is done to fully understand the causes. There was also discussion about whether or not somatic genome editing could end up being passed on to the next generation, which in theory, it can – the argument here was that the effects of editing a gene are so complex that each case is different and should be fully researched in order to understand the potential risks, before assuming that somatic genome edits are genetically isolated (i.e. only affecting a single person). The lack of certainty was problematic although after realising this, people still adopted a position in support of research to gather more information about what can be done and increase our level of certainty.

***"If you cut the genome, e.g. as with those twins in China, how do you know you [took] just what you want away? You may not know now how the genes work and there is a risk that you cut things that we only realise are important in the future."***
*Event 2, Stockholm*

### 4.1.2 Views of genome editing plants and crops

In the first event in Sweden we discussed a very similar case study around genome-edited potatoes. The first time we discussed this, the comments were more neutral/positive. Either people could see the benefits or they didn't see the harm in trying. With this future possibility case study, the arguments were more balanced. It also seemed that the genome-edited crops were being compared more directly to the examples of human genome editing.

The positive attitudes around genome-edited crops and plants revolved around our food consumption having a less negative effect on the environment and solving hunger issues. People discussed that it would be beneficial to be able to grow more crops closer to home to avoid shipping. Also crops that would be less intensive to farm and require less water could also have a positive impact on the environment. Participants were also very positive about editing crops to make them more nutritious in areas where famine was prevalent.

***"I find it hard to see anything negative about this. In the future, we must reduce freight and transport of goods, and this is a way of doing it."***
*Event 2, Stockholm*

People also discussed if there could be health benefits to genome-edited crops. If they could increase the nutritional content of food this was seen as positive by some, but not all participants.

***"If I get more intelligent, I'd eat!"***
*Event 1, Stockholm*

The tone of some of the discussions made genome editing crops sound slightly frivolous or a waste of resources. Many people commented why would we do this when there are many serious diseases to work on first. There was also a large concern over safety. People were not convinced that the technology is safe although if it could be proven that it was safe, they would eat genome-edited food. This led to a discussion about transparency in research and in food labelling. Participants said that they needed to know more about what happened to their food so that they could judge for themselves whether it was safe or not.

***"Feels weird. What's wrong with regular eco-bananas?"***
*Event 2, Stockholm*

### 4.1.3 Views of genome editing animals and livestock

Discussions around genome editing in livestock were mixed if not slightly negative. **People were concerned about safety, especially with animals that would eventually go into the food chain.** There was also a discussion as to whether genome editing was an appropriate way to fix problems in animal husbandry or whether the conditions of the animals should be addressed first. It was pointed out that using genome editing could help animals to survive in worse conditions which would facilitate deteriorating animal welfare conditions. In general, even if there was a positive discussion around genome editing in animals, people were concerned that the point an animal's genome is edited tended to represent a single point in a long chain of events. The gene and gene products interact in many ways throughout the course of an animal's life and even after when it becomes a foodstuff and is eaten. Not understanding these intricate interactions made people uncomfortable and led to a lot of questions and discussions about uncertainty.

***"This is not helpful. We need to review animal conditions and not adapt animals to poor animal conditions."***
*Event 2, Stockholm*

**There were some positive examples raised,** for example to treat genetic conditions that arose as a result of selective breading in dogs. It was also thought to be generally positive that if there was a genome editing solution that would replace the need to give animals antibiotics, this would be far more advantageous. There were also some medical examples discussed such as editing pigs to be able to grow organs which could be transplantable to humans (known as xenotransplantation) or eradicating the ability for mosquitos to carry and spread malaria. While people saw the benefits, they were still concerned that there were too many unknowns in each case to make it safe.

***"This malaria mosquitoes, do we know how it affects others in the food chain? What happens to all the other animals? If all mosquitoes disappear, do all the birds die?"***
*Event 2, Stockholm*

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

**Participants were mainly concerned that germline genome editing could be used to create a "superior race" of people with "better genes" than everyone else.** People were uncomfortable with the fact if we started editing germlines to cure important diseases, then it may be difficult to stop it being used in more unethical ways.

In the discussions, editing the **germline felt very permanent and this raised some ethical questions about how treatments could possibly be administered.** If the state provided treatments for conditions that were a significant burden for individuals and the state, could they then force people to have their germline edited. There were also concerns about how the decisions would be taken as to which diseases would be treated if not all treatments could be afforded.

Participants also discussed risk. **The possibility of something going wrong was compounded by the fact this error would be passed on from generation to generation.**

***"If research becomes so safe that it can eliminate HIV. Then I still think that you should stick to somatic changes instead of hereditary."***
*Event 2, Stockholm*

### 4.1.5 Views on heritable genome editing for non-medical purposes

This case study was viewed very negatively on the whole. A major concern was that people likely to change their personal traits would have the monetary means to do so themselves. This would then be a driver for inequality where the wealthy could afford to give themselves "superior" genes. This raised a lot of questions about how society would then function and whether it would be necessary to treat genetically enhanced humans differently in hospitals or if they would have better insurance terms.

***"I think it seems terrible if you're going to be able to change the hair and eye colour of your children. Or create super athletes. I think it seems awful."***
*Event 2, Stockholm*

There were some participants who viewed human enhancement using genome editing in the same light as cosmetic surgery. They argued if someone is going alter their body or even just dye their hair, then why is it a problem to do this genetically? Even in the case of sports where "genetic doping" could be used to give athletes an unfair advantage, some people thought that genome editing might help to level the playing field if everyone was allowed to do it. The majority of participants were opposed to this however and felt that genetic doping was unethical and should not be allowed in sports.

***"People dye their hair anyway, what's wrong if you change it genetically?"***
*Event 2, Stockholm*

The discussion raised the question of whether society should be actively against using genome editing techniques such as CRIPSR/Cas9 for human enhancement. This produced a more divided response with some participants agreeing strongly that it should be banned and others feeling that a total ban was too much.

## 4.2 Implications for the ORION partnership

The implications for the ORION partners in terms of communication are clear. Participants very quickly got a grasp of the ethical issues arising from each case study. One of the main reasons for rejecting genome editing in any given case is that they did not have enough information to be able to work out if it was safe or not. For this reason, ORION partners should evaluate how they communicate research around research involved in genome editing and specifically how the risks are communicated.

There was also discussion about transparency which is something that the ORION partners can work on. Research processes need to be more open and more transparent so that members of the public who are affected by the research do not feel that information is being kept from them. The participants wanted to be able to make informed decisions, many of them changed their mind during the discussion in light of new ideas or new information presented. This represents an opportunity for ORION partners to produce communication structures and strategies that fully inform stakeholders about genome editing technology.

# 5 Communication and engagement

A key objective of this public dialogue for VA 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 VA 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'[15] created for the purpose of these public dialogue, in collaboration with artist Emilia Tikka and one of the ORION partner organisations (MDC, Germany), and were asked to reflect on it.

## 5.1 Communications context

VA organises many events and activities aimed at stimulating dialogue between researchers and the wider society and develops and tests new formats for dialogue in Sweden. In addition, VA acts as the national knowledge hub for public engagement and science communication, disseminating knowledge and experience, gained by itself and others, and developing toolkits and best practice guidelines.

Citizen science is another field in which VA also has thorough experience and expertise. Since 2009, VA has been conducting an annual large-scale citizen project – mass experiments, with schools across Sweden on different topics as biology, climate, media, and astronomy. VA is also raising awareness of and expanding community participatory research and the network of Science Shops across Europe.

VA also carries out qualitative and quantitative studies, with the aim of increasing knowledge about the relationships between science and society at large. This includes an annual survey into the Swedish public's general attitudes towards science and researchers as well as more specific studies into societal groups such as journalists, teachers and the business community.

## 5.2 How should organisations like VA engage with the public around genome editing technology?

In the remainder of this chapter we offer our ideas on how best to engage with the public about genome editing technology, based on the views of participants in this dialogue.

### 5.2.1 What should organisations like VA be saying to the public about genome editing technology?

Transparency is key when it comes to communication with the public. Participants of the dialogue didn't just want to know about the end result, they wanted to know the details. They wanted to know how research had been done and who was funding it. The represents a challenge for the ORION partners. Research findings published in popular press tend to be short and concise summaries of results or applications of research, with

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

little room for expansion or nuance. ORION partners must find was to communicate with the public so that they can easily access all of the information they need to make informed opinions.

***"I find it difficult to find nuanced information. I want to know what their agenda is. And if I don't know, I'll stop reading because I think they want me to be for or against."***
*Event 2, Stockholm*

People were surprised about how much they learned at the public dialogue and how important the discussions were. They were also surprised that this was not debated or publicised more in the popular press. ORION partners need to find ways to present the important information to the public via media that they already use to get information.

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

Participants at the dialogue were pragmatic when it came to making decisions and finding the right ethical ways to use genome editing techniques like CRISPR/Cas9. For example, some people were totally against editing of embryos but after a discussion, most people agreed that it would be acceptable if the embryos were left over from IVF but not if they came from abortions. This shows that the public need to be better informed about the technology where possible, but also given a choice or a say in the way genome editing is applied.

***"You get a foundation from us ordinary people, but it's a huge job."***
*Event 2, Stockholm*

Researchers at institutes should be ambassadors for their research and be able to explain it well to the public. This is not necessarily in the skill set or job description of researchers now and this is a significant challenge for the ORION partners. Communication experts within ORION could be responsible for training researchers in how to communication complex subjects to the public. ORION could also use connections to funding bodies and lobbying connections to advocate for more resources be allocated to communication in research projects.

***"If you can't communicate your research to the person who's going to use it, that research will fall down."***
*Event 2, Stockholm*

This dialogue has shown that it is important to see the public as a stakeholder in research, especially when they are likely going to be the end user/consumer as is the case with genome editing. This means typical one-way communication should be replaced by two-way communication, where ORION partners are set up to receive and respond to comments and questions from the public. The public dialogues were an excellent example for this, however, lower cost solutions should also be found so that two-way communication with the public can happen more regularly and at a larger scale.

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

Much of the discussion at the public dialogue revolved around risk. This is a complex subject in the context of scientific research because there are a lot of unknowns, both for researchers and especially for the general public. However, understanding risk is not itself inherently complex and people are good at evaluating risk and taking decisions. To this end, ORION partners should try and communicate risk to the general public, including how new research findings affect how risky or safe a procedure is.

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

Participants were happy to be involved in the public dialogue. Many expressed that it was good to have their opinions heard and learn about the details of genome editing technology. Some participants even suggested that they would be happy to take part again in the future and expressed interest in seeing the results from the public dialogues held in other countries. In general, people also realised that public dialogues are not the most effective way to communicate with many people and suggested that this communication channel would have to be supplemented with things such as TV adverts, Netflix documentaries, advertisements in the metro and on social media.

***"I want to know what's going on now. I want to know what happens not just the larger context in which it will appear."***
*Event 2, Stockholm*

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
- VA website
- Social media
- Citizen science
- Citizen's forums

- Printed media
- Public Science fairs
- Exhibitions showing the technology and Open Days
- Theatrical performances

In general, participants had a strong preference for TV and social media as methods for communication. This not only represented their own preferences for receiving information, but also where they believed ORION partners could reach the most people.

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

| Method | Pros | Cons |
|---|---|---|
| Animated videos | Easy to consume. | Perhaps too simple and can hide what the motives are behind it. For example, the video shown at the public dialogue was criticised for being too positive and not nuanced enough. |
| Videos of scientists talking about their work | Good to hear from scientists. | Media is not always scientists' strongest skill. |
| Television | Strong preference among participants. Wide reaching and easy to understand. | Not everyone watches television nowadays. |
| Academic journals | | Not many participants had read one so reach is limited. |
| The VA website | Important to have a website with up to date information. | Might be difficult to find if you don't know about it. |
| Social media | Also strong preference among participants. Where most people get their information and easy to engage. | Difficult to know what is right or wrong in social media. |
| Citizen's forums | Very useful. | Not easy to engage a lot of people. |

| | | |
|---|---|---|
| Printed media | | Seen as obsolete. |

**None of the participants felt that publishing in academic journals should be a high priority which is sometimes the only place scientific work is published.** Other methods received varying degrees of support but the most popular were TV and social media as these were seen as the simplest ways to share information that was easy to understand. Print media was very poorly rated as it was seen as becoming increasingly obsolete by most of the participants.

ORION already has a social media presence which is supported by the social media presence of all the ORION partners. **A clear first step is to start communicating the types of information requested by the dialogue participants through these channels**. Also, TV was widely considered to be a good way of communicating with the general public, therefore **ORION should therefore plan a strategy for getting more exposure on national television networks** in the partner countries.

### 5.2.3 Views of the 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 means 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 '*Trajectories of longevity and CRISPR*' (*ÆON*). Images of the artwork can be found on Emilia Tikka's website.[16] 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.

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

**Figure 5.1: Images of AEON Trajectories of longevity and CRISPR**



*ÆON* was publicly exhibited in Sweden at the National Museum of Science and Technology (the venue for the public dialogue events), and prior to the first event participants were invited to attend the launch of the piece. Emilia Tikka attended the first event and gave a brief talk to participants about the art piece, introducing it and speaking about the societal implications of the scenario it depicts. The art piece was then shown to participants again during the second event and discussed in detail.

An aim of the art piece was to encourage people to discuss ethical or controversial issues related to genome editing technology, or to make them feel differently. **The art piece was very effective at stimulating discussion around genome editing**. Ironically, even when participants stated that it didn't help, this very statement led to a discussion around the art piece and genome editing. The art piece was very good at drawing out opinions and emotional responses from people.

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

The point was raised that perhaps the art piece would not have been successful if it was not part of the public dialogues as participants had learnt a lot about genome editing technology and had been provided with a lot of information to be able to consider ethical and societal implications. To this end, it is possibly important to make sure art pieces are included as a larger part of a whole project. **The piece stimulated discussion but in the context of the public dialogue where participants had access to a lot of extra information, experts and were guided through topics by discussion leaders.** This may be particularly true of the events in Sweden where participants had an opportunity to see the art piece before the events and were able to meet, hear from and speak to the artist during the first event.

***"[The art is] Good as a way to make it real for people. When you get to touch it, it becomes more real."***
*Event 2, Stockholm*

Some participants perceived the artwork as being quite boring and bland. These participants would have preferred a more interactive exhibition, perhaps with multimedia including videos. There were complaints that there was no back story to the art piece, so it was difficult to understand the point it was trying to make. It was also pointed out that very little of the discussion at the dialogue was about aging and longevity, so perhaps the art piece should have focused around curing disease. **Despite some negative sentiment, participants generally accepted that art does matter and is a good communication medium, providing people have time to see it and think about it properly.**

**Participants thought that art like this piece was an important way of making its audience think and feel, which they felt an important element of communication that is often missing.** People also commented that this can only work if a lot of people can see it. There was also a view that **artwork with this purpose should go on tour and should be featured in prominent places where many people will have the opportunity to see it**. Participants mentioned putting the artwork in metro stations or in central places in Stockholm.

***"I think it's a great way to reach out and get people to start talking."***
*Event 2, Stockholm*

There were also comments that it was difficult to convey all of the nuanced information and detail needed to discuss genome editing in the art piece. However, there was a general consensus that people take in information in different ways and as long as an art piece was not the only communications channel used to communicate about genome editing technology, it would probably be a useful way of stimulating discussion and raising awareness.

***"I have two daughters, they have a completely different way of absorbing information."***
*Event 2, Stockholm*

# 6 Conclusions & Recommendations

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

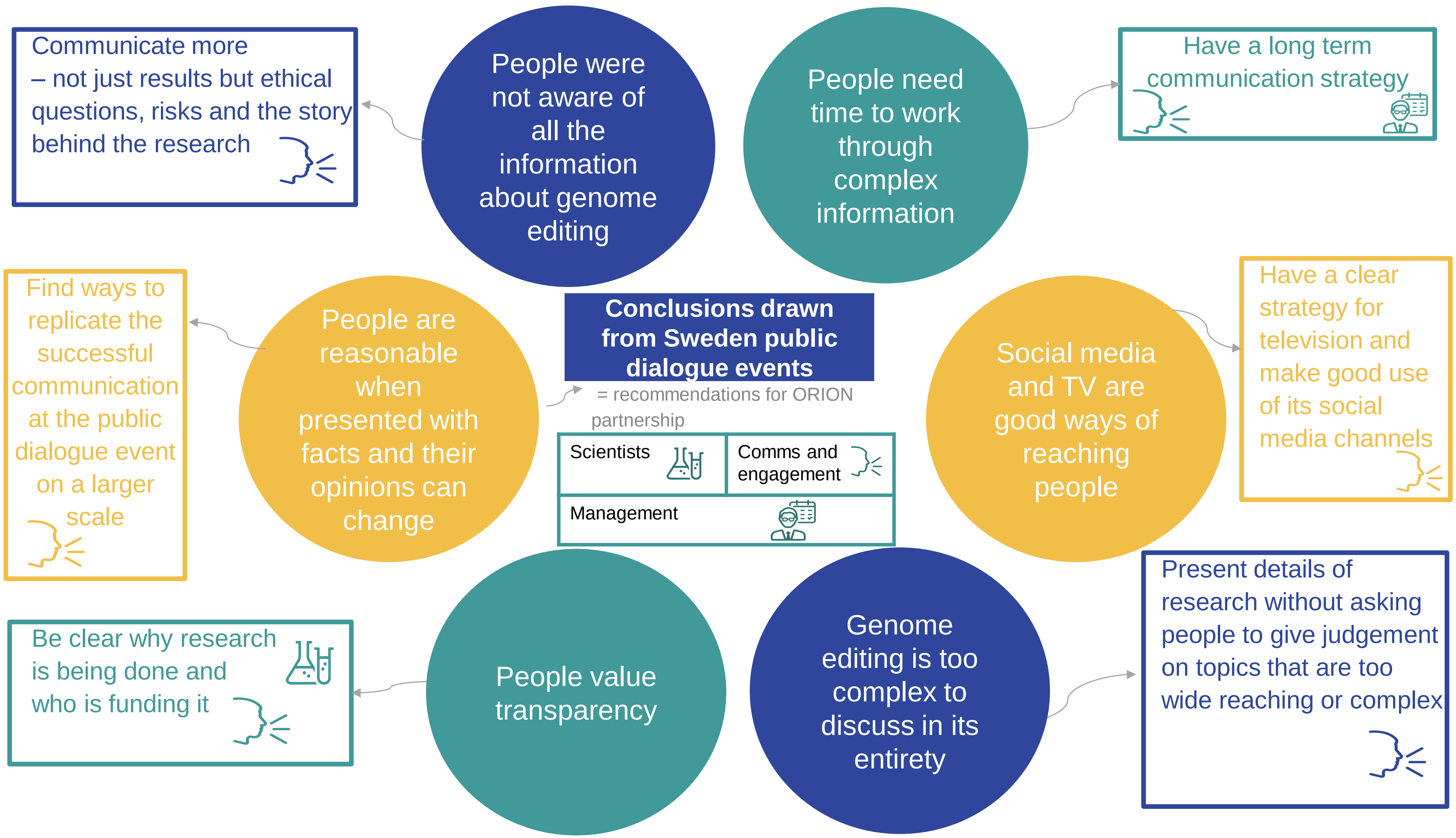
**Table 6.1: Table of conclusions & recommendations**

| | Conclusions | Recommendations | Recommendation for: |
|---|---|---|---|
| 1 | People were not aware of all of the information about genome editing. | Communicate more – not just results but ethical questions, risks and the story behind research. | • Communication and engagement specialists should ensure that there is more information available to the public, and therefore more discussion publicly about genome editing technology |
| 2 | People are reasonable when presented with facts and their opinions can change. | Find ways to replicate the successful communication at the public dialogue event on a larger scale. | • Communication and engagement specialists should explore effective ways to run similar events |
| 3 | People value transparency. | Be clear why research is being done and who is funding it. | • Communication and engagement specialists should consider how organisations as a whole can be transparent about work they are doing<br>• Scientists should consider ways they can be transparent about the research they are conducting, and why they are doing this research |
| 4 | Genome editing is too complex to discuss in its entirety. Individual cases using genome editing techniques need to be | Present details of research without asking people to give judgments on topics that are too wide reaching or complex. | • Communication and engagement specialists should consider how information can be presented |

| | | | |
|---|---|---|---|
| | judged on an individual basis. | | in easily accessible ways that promote healthy debate |
| 5 | Social media and TV are good ways of reaching people. | Have a clear strategy for television and make good use of its social media channels. | • Communication and Engagement specialists should consider television and social media as methods of communicating with the public |
| 6 | Discussions in the second event were more informed and nuanced. People needed time to work though complex information. | Have a long-term communication strategy in ORION. | • Communication and Engagement specialists, alongside management within the ORION partners will need to consider the most effective communication strategies long-term |

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 |
|---|---|---|
| Fredrik Wermeling | Karolinska Institutet | Researcher |
| Anna Maria Fleetwood | Vetenskapsrådet | National Expert SwafS Horizon 2020 |
| Annakarin Svenningsson | LIF - The research based pharmaceutical industry | Communication manager/Press officer |
| Heather Marshall-Heyman | Swelife | Project manager |
| Lotta Eriksson | The Swedish National Council on Medical Ethics | Head of secretariat |
| Åsa Silfverplatz | Riksförbundet Cystisk Fibros | Patient group representative |
| Erik Malmqvist | University of Gothenburg | Researcher |
| Torbjörn Tännsjö | Stockholm University | Researcher |
| Ana Nordberg | Lund University | Researcher |
| Ebba Carbonnier | Swelife | Advisor |
| Carina Knorpp | Government | Advisor |
| Catharina Rosqvist | Government | Advisor |
| Johan Brun | LIF- The research based pharmaceutical industry | Doctor |

# 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 | |
| Lotta Eriksson | The Swedish National Council on Medical Ethics | Head of secretariat |
| Fredrik Lanner | Karolinska Institutet | Assistant Professor |
| Fredrik Wermeling | Karolinska Institutet | Researcher |
| | Event 2 | |
| Fredrik Wermeling | Karolinska Institutet | Researcher |
| Nadine Schweizer | Vinnova | National Contact Point |
| Lotta Eriksson | The Swedish National Council on Medical Ethics | Head of secretariat |

# Appendix C: Case Studies shown to participants

## Genome edited potatoes

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

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

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

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

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## Understanding how cells function

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

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

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

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

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## Editing embryonic stem cells

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

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

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

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

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# 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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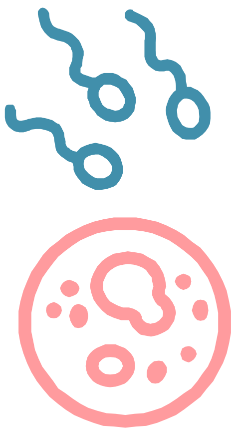
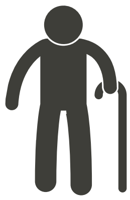
## Future possibility 1: Genome editing human embryos

- 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.



# Future possibility 2: Changing traits in humans

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



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# Future possibility 3: Genome editing animals

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

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

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

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# Future possibility 4:
# Genome editing plants & crops

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

# Appendix 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 | ORION Open Science - 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[17] | 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) |

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

Swedish Review Group members

| Name | Organisation | Role |
|---|---|---|
| Ben Libberton | VA | Science Communicator |
| Björn Kull | Karolinska Institutet | Head of Grants Office |
| Gunnar Sandberg | Vinnova | Health Department Programme Manager |
| Anna Maria Fleetwood | Swedish Research Council - Vetenskapsrådet | Swedish Nation Council on Medical Ethics |
| Lotta Eriksson | Head of Secretariat | Scientific Secretary |
| Annakarin Svenningsson | LIF - the trade association for the research-based pharmaceutical industry in Sweden | Communications Officer |
| Maria Hagardt | VA | International Relations & Communications Manager |

# Appendix H: Babraham Institute & Ipsos 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[18] | The Babraham Institute | Public Engagement ORION Open Science Project Officer (maternity cover) |
| Tacita Croucher | The Babraham Institute | Public Engagement Manager |
| Hayley McCulloch[18] | 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[18] | 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 |

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

| | | |
|---|---|---|
| Pontus Jansson | Ipsos Sweden | Planning & Recruitment |

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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.