Public dialogue on genome editing

Germany country report

By Ipsos MORI Social Research Institute 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.

Contents

List of tables

List of figures

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.

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

Members of the Advisory Group and German Review Group who have agreed to be named in this report are listed in Appendix E. The Babraham Institute's public engagement team and Ipsos project team who contributed to this project are listed in Appendix F.

[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 of the countries where ORION partner institutions are located; the UK, Germany, Sweden, and the Czech Republic. **This report details findings from the dialogue held in Berlin (Germany).** During the events, members of the public discussed current research applications of genome editing technology, possible future uses, and explored the best ways for ORION partners to engage with the public about genome editing.

Views of key societal challenges and solutions

First, participants were invited to think about key challenges currently facing society and how those challenges could be solved. **Key challenges identified related to the distribution and access to resources such as food, climate change and our environment, health issues, as well as poverty in old age.** While none of the participants mentioned genome editing technology as a solution to these problems, **they proposed solutions that genome editing technology might help to deliver**. Technology, innovation, science and research were considered big opportunities for the future.

Views of basic research and genome editing techniques

Participants overall had limited understanding of key biological concepts such as DNA, genes, cells and the process of basic research.[5] When they learnt about genome editing technology, **participants were positive about it because of its potential applications for medical purposes**. They could also see **value in acquiring and sharing knowledge from basic research.** At the same time, participants expressed **fears about access to genome editing applications/treatments**. They questioned whether these would be covered by public health insurance, and if not, thought they could worsen inequalities in the class divide in the healthcare system.

Views of possible future uses of genome editing

Participants discussed a range of future possible uses of genome editing applications. **Participants saw the benefits of germline genome editing[6], but considered the need for continued oversight and regulation. They came to the overall conclusion that somatic genome editing[7] is more applicable than germline genome editing for now** as it was viewed as being more controllable. They were not supportive of using genome editing technology to edit animals and livestock because of concerns for animal welfare and worries about human consumption of genome-edited livestock. Participants were also not supportive of genome editing for cosmetic uses or human enhancement. This was seen as unnatural, and likely to worsen existing inequalities. Participants

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

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

were unsure about genome editing of plants and crops; they could not easily see the relevance of this and feared the effect it could have on wider natural ecosystems.

Communication and engagement

Genome editing was considered of importance to the entire public, and participants thought everyone should have the opportunity to form an opinion on the subject. Therefore, **participants called for transparent and accessible information** about the genome editing research that is being done, ideally via the MDC's website. To participants, transparency meant communicating both negative and positive implications of its use.

Participants reported trust in scientists because they are experts in their field, and it was felt that clear communications from them to the general public reaffirmed this trust. Resultingly, knowing and understanding scientists' values would diffuse worries about the potential harm genome editing could do. Additionally, participants felt that highlighting the regulatory European framework within which the MDC operates could also help to build public confidence.

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

Participants felt communications about genome editing first needs to reach a broad spectrum of society, and in a second step communication can then become more specific and filter down to more specialised content. TV and social media were seen as the two key means to reach the wider public, as well as video content (including videos of scientists). Widespread education about genome editing was also seen as important and participants felt it **should be included within school curricula** (which it currently is). Citizen Science was not a widely known format but raised interest among participants. The public dialogues were liked as a format for engaging the public as they give people the chance to be heard and interact with scientists, though participants felt they have a limited reach and relatively high cost compared to other methods.

Participants were shown an art piece – *ÆON*[8] – depicting a hypothetical future scenario where genome editing technology is used to preserve youth. This was **successful in provoking discussion and led participants to reflect on the ethical challenges.** Discussions were focussed around the risk of overpopulation vs. fulfilling one's individual desire to live forever; health of body vs. mind; loneliness, and the possibility to divide society along the lines of opponents and proponents of using the technology to prolong life. However, the extent to which the art piece can provoke ethical discussions outside of a moderated dialogue with additional information is unclear as the role of genome editing technology within the art piece was not fully understood.

Key conclusions

Participants were positive about the possibilities genome editing technology could bring, particularly relating to public health. However, they wanted reassurance that the technology would not worsen existing inequalities or have negative environmental effects. Participants wanted information from the MDC to be transparent and accessible, with key methods of communication seen as TV, social media, video content, and dissemination through schools. The art piece successfully sparked discussion in the context of a public dialogue.

---

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

1 Background, objectives, and method

1.1 Background

1.1.1 About ORION

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

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

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

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

Five Research Performing Organisations:

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

Two research funders:

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

Two research supporting organisations:

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

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

1.1.2 About this public dialogue

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

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

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

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

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

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

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

Vetenskap & Allmänhet (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 Germany. 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 Germany 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 differences across countries.

1.3.1 Governance

International Advisory Group:

An international Advisory Group was convened to provide oversight and governance of the overall project (throughout this section, the term 'project' is defined as the series of public dialogues in four countries). The Advisory Group membership consisted of stakeholders with knowledge and expertise in genome editing, the ethical issues associated with the technology, and science communication as well as ORION staff from each of the four partners involved in the project. A list of Advisory Group members who have agreed to be named in this report can be found in Appendix E.

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 German Review Group membership consisted of staff from within MDC.

Ipsos Germany & Ipsos MORI

Ipsos staff at the Ipsos Berlin office in Germany were responsible for arranging and moderating the stakeholder workshop and public dialogue events in Germany, including recruiting participants and analysing and reporting findings from these. Ipsos Germany 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.

MDC staff:

ORION staff within MDC worked directly with Ipsos Germany in Berlin to coordinate the stakeholder workshop and public dialogue events in Berlin. This included providing the venue and catering for the events. MDC also provided examples of research they conduct 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:

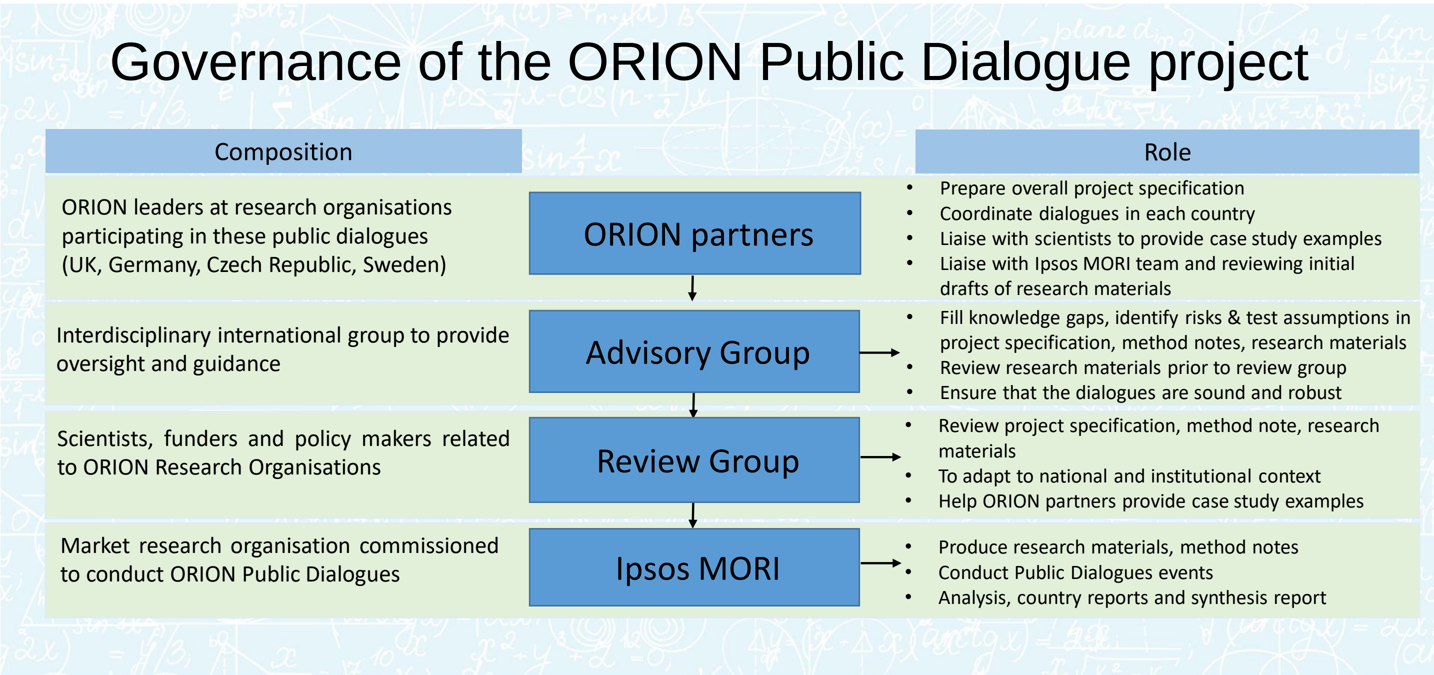
- Project specification – Initial document produced by the ORION consortium that outlined the background, context and rationale behind the project, the aims, objectives and proposed methods, the expected outputs and outcomes, anticipated risks, and proposed method of disseminating findings. It also outlined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

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 MDC with stakeholders including experts in genome editing and science communication and engagement.

4. Findings from the stakeholder workshops were used to help develop material for the public dialogues. For the events in Germany, MDC provided four examples of their research using genome editing to present to the public in the form of case studies.

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

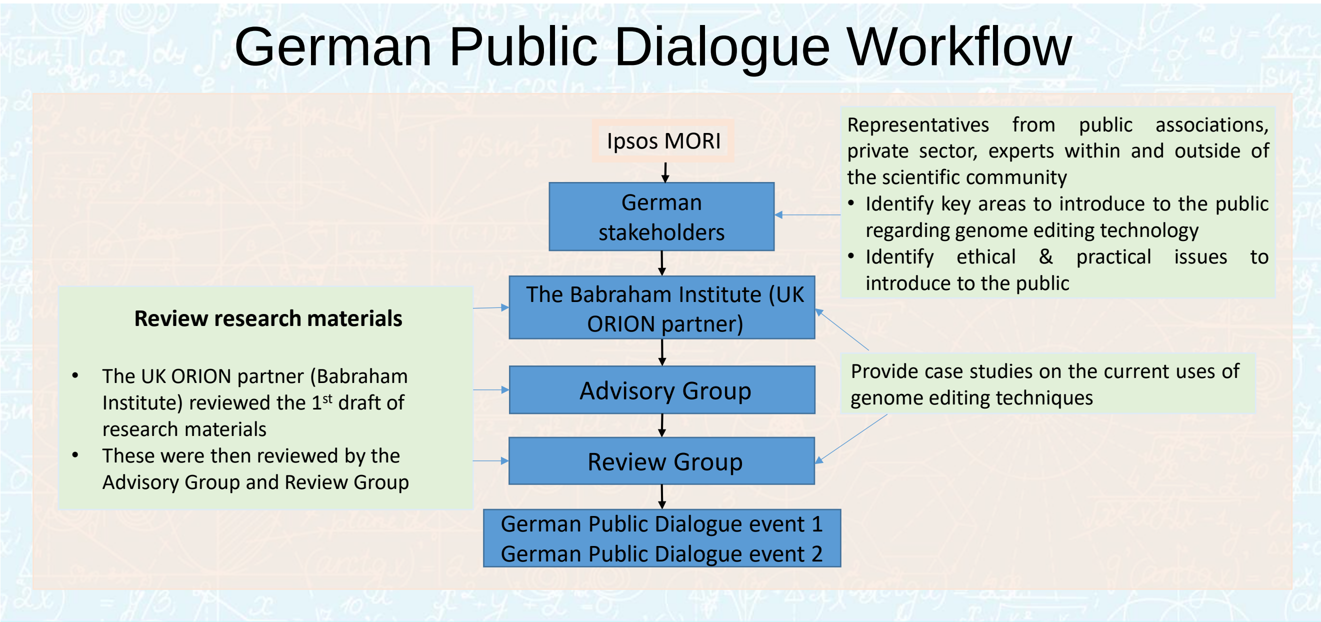
6. A pair of public dialogue events were held with members of the public in Berlin.

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 German Public Dialogues



1.3.3 Stakeholder workshop

A workshop was held on 23rd September 2019 at the at the Max Delbrück Center (MDC), Berlin, Germany, with 13 of the Institute's internal and external stakeholders (i.e. people with a vested interest in genome editing technology, some working at MDC and others working for other organisations) plus Zoe Ingram from MDC as a silent observer. The purpose of this stakeholder workshop was to provide diverse insight for the design of the materials to be shown during the public dialogue events. Participants were identified by ORION staff at MDC, in collaboration with Ipsos MORI, and included a range of experts who brought a perspective on the technical and ethical issues associated with genome editing. These included scientists using genome editing techniques but also other experts who could express views from an ethical or public engagement context. A breakdown of the stakeholders involved in the workshop is provided in the table below.

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

Stakeholder type 1	Stakeholder type 2	No. Stakeholders
Experts in life sciences	Scientists (nutritional, agricultural and medical science)	3
	Post-doctoral researcher (medical science)	1
Experts outside of life sciences	Reproduction expert of Federal Association	1
	Education/Communication expert	2
Industry representatives	Industry (communications and policy advice for ethical and health issues)	1
Public Engagement Specialists & Journalists	Public Engagement specialist	4
Representative bodies	Public Associations regarding genome editing	1
Total number of Stakeholders: 13		

1.3.4 Public Dialogue events

Two dialogue events were held in Germany with members of the public to discuss genome editing technology. Both took place at the MDC offices, in Berlin, Germany. Twenty-nine members of the public took part in both events.

Recruitment of participants to the events was undertaken by Ipsos Germany with the help of a third-party recruitment specialist. Ipsos MORI developed recruitment materials which Ipsos Germany and their supplier used to recruit participants to the events. These recruitment materials consisted of a set of documents which provided information about the research to potential participants, incorporated a screening questionnaire which collected information about participant characteristics, and had space to record contact details if participants confirmed they were available and interested in participating.

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

The screening questionnaire asked about demographic factors including participants' gender, age, 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.

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

Location	Urban location	2
	Suburban location	9
Gender	Male	15
	Female	14
Age groups	18-30	8
	31-44	6
	45-64	8
	65+	7
Migration background	Without migration background	22
	With migration background[11]	7
Child status	Children at home	8
	Children sometimes at home	4
	Children have left home	7
	No children	10
Employment status	Employed	16
	Unemployed	13
Attitudes to genome editing before the events	Comfortable with the concept	12
	Uncomfortable with the concept	10
	Don't know	7
		Total number of Participants: 29

[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 9/10 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 MDC. Three experts attended the first event, and three different experts attended the second event. At the first event, three postdoctoral researchers working at the MDC joined as experts. At the second event one group leader, one postdoctoral researcher, and an ex-scientist who is now a public engagement officer attended as experts, all of whom worked at the MDC.

Event 1: The first event was an evening workshop that ran between 6.15pm and 9.15pm on Thursday 6th November 2019. The focus of this event was to give participants the minimum amount of information needed to engage in discussions about the use of genome editing technology and the issues arising from it. Participants were informed about key biological concepts including DNA, genes, the genome, and proteins, this enabling them to discuss different research uses of genome editing technology. Once participants had learnt about these biological concepts, they were shown and discussed case studies based on MDC's research using genome editing.

Event 2: The second event was a day-long workshop running between 10am and 4pm on Saturday 16th November 2019. During this event, the case studies outlining examples of MDC's research were re-introduced to remind participants about the type of research conducted by MDC, and this was followed by a discussion of possible future uses of the technology. The afternoon involved discussion of how best to communicate and engage the public around genome editing technology. Part of this conversation involved capturing participants views on an artwork that was specially commissioned for the dialogue, which depicted a hypothetical far off scenario where genome editing technology has enabled the slowing down of the ageing process.

Post-events analysis: With participants' consent, discussions at the events were recorded and notes were taken. 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 fact that the events were hosted in an MDC building could have also contributed to this. 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, and;
  - 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.
- Paying participants financial incentives for participating may have influenced participant opinions and lead to response bias. Paying incentives compensates participants for their time and effort and makes it much more likely they will remain involved and committed as they will feel compensated. Paying incentives to participate also helps to overcome a skewed sample, where if people willing to participate without compensation were recruited, the views of less engaged citizens could be missed. The possibility of the use of incentives biasing responses was mitigated by making clear that incentives came from the organisation independently delivering the work (Ipsos) rather than MDC itself. Participants were also recruited according to quotas, including sociodemographic segment, to try and ensure participants reflected a broad range of financial backgrounds.

2 Views of key challenges facing society and solutions

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

2.1 Public views of key challenges facing society

The key challenges identified related to distribution and access to resources such as food, climate change and our environment, health issues, as well as poverty in old age.

The key challenges discussed were intertwined. Climate change affects food supply, health is affected by the food we eat, and poverty affects access to healthcare. Since key challenges are related to resource allocation, which was feared to become more unequal, there was fear about rising inequality.

Health was considered a key challenge, because healthcare infrastructure does not meet peoples' needs and current demand. Germany has an aging society – and thus an increase in health problems – making this an even bigger challenge for the future. Whilst access to healthcare is currently not equally distributed across society, where you live has an impact on access to health care professionals, treatment, and therapy.

"[It is a challenge to] ensure access to health in a context of social inequality. How can people living in the countryside obtain the same foundation as people in the city, to access treatment and therapy?"
Event 1, Berlin

Healthcare access does not only differ according to where you live, but also by your type of insurance. Public healthcare does not cover the same therapies as those available to privately insured patients, and where there is access it is severely limited. There was thus the perception of a rising two tier healthcare system.

Food challenges were linked to limited resources and the implemented short-term solutions leading to unintended – or unknown – consequences. For example, mass plantations leading to monocultures and the impact of genetically modified food were key concerns. Participants thought these issues were worrying, because proposed solutions to these food-related problems are rooted in changes with unknown implications as well as lack of regulation.

"Mass plantations of crops. These are intrusions, where it is not clear what their long-term implications will be for nature. We speak about climate change and want to fix it with changed crops and damage biodiversity. We need strict boundaries. That is the biggest challenge."
Event 1, Berlin

Furthermore, food also poses a challenge to society, because uncontrolled consumption can have a negative effect on our health.

Since the key challenges are intertwined, the potential solutions were equally so. Prevention emerged as a key theme. Currently, access to preventive care is limited. There are two main reasons for this. For one, public health insurance does often not cover it. Secondly, because demand of healthcare exceeds supply, waiting times are seen as a barrier to make use of preventive diagnostics.

"You have to pay everything yourself. For example, the cancer check-up, you can only get it every three years. Same with teeth preventive care. What you get from the doctor are standard results with which you cannot do much, doctors only do something when you pay them."
Event 1, Berlin

Alongside the healthcare system, pharmaceutical companies were seen as a barrier. The economic interest of companies for people to be sick leads in this view to pharmaceutical companies putting pressure on governments to limit spending on preventive care.

It was felt that prevention could in part be achieved through greater education. Health issues are increasingly lifestyle related, e.g. stemming from high sugar or fat consumption. Improving education on the relationship between what we eat and our health could therefore reduce lifestyle related health problems. Government regulation was suggested as a way to curb lifestyle related health challenges through education on unhealthy foods. There was some fear however, that the government lacks independence from the pharmaceutical industry.

"The state does not have the control. Industry is producing things and the state is not doing anything about it. E.g. advertisements for Fruchtzwerge [fruit yoghurts targeting children]. They should ban these."
Event 1, Berlin

Overall, people felt somewhat worried, because currently known solutions would require deep rooted changes.

2.2 Spontaneous views of solutions

Technology, innovation, science and research were considered to be a big opportunity for the future. Participants felt that technology had the potential to provide new ways of addressing old problems, for instance, through early optimised treatments and early stage diagnostics. However, there was some fear that technology will be used to develop "unnatural" solutions. Nevertheless, technology is not only considered a means to address challenges, but also as a way to engage the public and communicate challenges and solutions. At this point in the discussion genome editing technology itself was not considered as a possibility that provides technical solutions on challenges faced by society today.

3 Views of basic research and genome editing techniques

Prior to the public dialogue event in Berlin, Ipsos conducted a workshop with MDC stakeholders with expertise in genome editing from various backgrounds (bringing scientific, ethical, and public engagement perspectives). This stakeholder workshop helped to ensure that at the dialogue events, the public were presented with information and perspectives collated from a wide range of sources. The purpose of this workshop was to establish what information experts felt the public would need to engage with the different ways researchers at MDC 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 MDC's research involving genome editing technology.

3.1 Participant starting points

Knowledge of key biological concepts and terms was limited, and some knowledge in this area did not equate to an awareness of genome editing technology and the current landscape of genetic research. Some had more knowledge on the subject, because they had a specific interest in science. Sources of information mentioned were one of Germany's most successful YouTube channels "Kurzgesagt"[12] as well as a Netflix series and science TV programmes.

"I had no access to it [the topic of genome editing]. I did not know before what you can do with cells. I did not know what DNA is, exactly. It is very interesting."
Event 1, Berlin

Limited knowledge meant that participants had many questions to start with. Broadly, these questions were around three key themes. The first was around the use of genome editing for medical purposes. Participants wanted to understand more about genome editing and gene therapy (information was provided by experts that this involves introducing genetic material into cells to compensate for abnormal genes or to make a beneficial protein). The second theme was about economic interest and lobby groups and how they impact research and application of genome editing. Lastly, but linked to the former category, were questions on regulation and ethics. Particularly, participants felt there was a need for an international agreement on genome editing. Overall there was a feeling that Germany and Europe need to play a pioneering role to shape discourse and application of genome editing.

[12] Example videos from the channel include explanatory videos on CRISPR/Cas9 and the debate around 'designer babies': https://www.youtube.com/watch?v=gUa2H8CcUjU// https://www.youtube.com/watch?v=ZAz1GutJGbg; last accessed: 10.12.2019

"The nation that is leading [in genome editing] will be setting the standards. When Europe takes up a pioneering role, we have the possibility to set the ethics and standards worldwide. You see how it goes also in other areas, e.g. through Facebook and Google."
Event 1, Berlin

Despite a lack of knowledge and awareness of genome editing technology prior to the public dialogue, the public's initial reactions were positive. Generally, participants felt hopeful that genome editing would be beneficial to the general public because of its potential applications for medical purposes.

Excitement for genome editing was strong because participants had largely been unaware of how great the possibilities of this technology are.

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

Becoming aware of the opportunities of the technology, the public felt hopeful that it may provide (relatively) cheap treatments, maybe even alternatives to treatments (e.g. chemotherapy), and enable us to live longer, healthier lives.

"It is a chance that in something like three generations all illnesses might be curable."
Event 1, Berlin

"You can impact personal lives positively and the health system saves money."
Event 1, Berlin

Genome editing technology was thus perceived as a potential solution to the problem of the challenges experienced in relation to the public healthcare system. Participants largely regarded the personal benefit, supposedly improved therapy and treatment (even for hereditary diseases), as outweighing initial ethical concerns. Having treatment options, having the possibility not to pass on diseases were considered factors that increase quality of life. Genome editing for medical purposes excited participants because many imagined a panacea against all ailments. Genome editing thus tapped into their human fear of sickness.

"When you are sick it is ethically acceptable to use genome editing because there is fear. Humans are fearful and want to try everything. I had cancer twice and survived it. I am not afraid [of genome editing]."
Event 1, Berlin

"To heal people [of sickness] everything should be possible."
Event 1, Berlin

There were also concerns about the use of genome editing technology. Fears about the access to genome editing applications/treatments remain. For one, participants feared that genome editing treatments may not be covered by public health insurance, meaning they would not benefit from those, worsening the class divide in the healthcare system. This raised the fear of being personally left behind and not benefitting when sick.

"You have to make sure it is not only available to the rich."
Event 1, Berlin

In addition, the question of access was raised in relation to an increase in life expectancy due to genome editing applications. The following questions arose: will the healthcare system be able to accommodate all the older people who live longer due to genome editing technology? How do we deal with overpopulation and will genome editing worsen this?

Participants realised that as well as there being benefits of the technology, there are also downsides and risks. Using the technology to improve health was considered normal and addressed our innate human need for security (through treatment options) and preservation (treatment options that avoid death). On the other hand, interventions into nature using the technology that do not solve a life-threatening human problem quickly raised ethical concerns.

"Barbra Streisand cloned her dogs. This goes too far. This is an intervention. This should not be done."
Event 1, Berlin

Next to "designer animals", "designer babies" were a key concern because of the risk that it will increase social inequalities. How participants felt about genome editing applications is thus closely related to its regulatory framework. There were concerns about the potential for abuse of the technology (e.g. in the areas of pharma and military).

"It [genome editing] is an instrument of power. It is the atomic bomb of health care. (…) It is either there for those who have the most money and can choose. One part [of society] will be left behind because it needs to be paid. The one who has the most money can live the longest and best life. (…) It can lead to a class society. It will be difficult to regulate that."
Event 1, Berlin

To summarise: people felt mostly excited because genome editing could address one of the key challenges of our time; healthcare. Excitement stemmed from the fact that participants hoped they, or their loved ones, will personally benefit. At the same time, they could be the ones to lose out if access is not guaranteed. Ultimately, the winners and the losers will depend on who sets the standards and makes sure genome editing is used in the public best interest. Regulation – ideally on a global level – was thus considered as essential. It provides peace of mind to the public and will ensure that genome editing will be used in the best interest of the public. It was recognised that even global regulations can be broken, but also that this should not stop research. The key issue will be to control what can be done with the results of the use of genome editing in research.

"Pandora's box has been opened (…) and we cannot take this technology away now. Now we can only influence the direction it takes, that it obeys ethical standards, that boundaries of species are

not overstepped. That everything is done for treatment and healing of humans. Not for the design of unborn life."
Event 1, Berlin

3.2 Views of basic research using genome editing technology

It was outlined that MDC conducts early-stage, basic research aimed at understanding biological processes, which may or may not lead to immediate practical applications. Once this was explained, participants could see the value in the acquisition and sharing of knowledge around basic research and saw how the technology had potential to achieve many of the societal challenges that they had previously identified.

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

Case study 1: Converting skin cells into egg cells – this case study discusses how MDC are exploring whether they can convert skin cells to egg cells in rhinos, a process which could help to address the near extinction of the northern white rhino.

Case study 2: How does titin affect heart growth – the case study looks at the work scientists have done to edit the titin gene in mice to understand why changes in genes lead to mice having different sized hearts. If they can understand this change then this might lead to them being able to correct this change in the future.

Case study 3: Understanding gene expression – this case study covers the work MDC are doing using CRISPR/Cas9 to find out which proteins are responsible for causing albuminuria in rats and zebrafish. This is a sign of kidney disease where the protein albumin leaks out of kidneys and into urine.

Case study 4: editing model organisms – this case study covers work MDC researchers are doing using CRISPR/Cas9 to re-create human cancers in mice in the hope of finding new medical therapies. They are looking at how the tumor cells have grown and whether the cancer cells develop resistance to certain therapies. They hope this will help them understand how patients can respond to chemotherapy differently.

3.2.1 Case study 1: Converting skin cells into egg cells

In general people were overwhelmed by the possibilities scientists already have. Many were not aware that technologies like these are already available. Positively, it was mentioned that it would be possible to undo mistakes, e.g. undo the extinction of animals caused by human beings. Jurassic Park comparisons were made straight away. However, many questions arose when participants thought further about the case study. Participants asked themselves what boundaries we must respect as using this technology could be a strong intervention into the ecosystem. It was unclear to participants if the northern white rhino faces extinction because of humans. A concern was expressed in relation to the use of genome editing to tamper with nature to resolve natural occurrences. In other words, participants only accepted the technology if it was to be used where humans were the cause of the extinction. Otherwise it would be too much of an intervention into the ecosystem to try and revive species that became extinct for reasons not relating to human behaviour. Participants questioned whether we can estimate the impact of such a technology. Here, participants were clear that regulations are needed. Another issue was that some people felt that a technology like this is not solving the major issue itself, which is the strong negative impact humankind has on the planet and on every single species living on it.

"There's a reason why certain species are extinct. Chaos is inevitable when free action is allowed."
Event 2, Berlin

3.2.2 Case study 2: How does titin affect heart growth?

This case study mentions a clear benefit for people. It is the healing or the prevention of an illness. This had a strong impact on peoples' support for this area of research. However, there were several concerns and questions that came up during the discussion. For example, how easy is it to adapt this research to make it not only beneficial for mice, but also for human beings? How easy or difficult is it to have possible unintended effects (where unintentional changes to the genome are made as a result of the editing technique) under control? Another dominant concern was the question over who the client of this research was or who was funding this research. This shows again the fear that a treatment will only be available for very few people and a perception that the pharmaceutical industry may be controlling the knowledge around this research. A major requirement is that access is granted to everybody, not only an elite group of people. Another area that people discussed on this topic was abuse of the technology in sports to achieve better athletic performances. This was highly rejected.

"Abuse of organs by athletes [is a concern]. Which can also be to the detriment of humans. That can get into problems."
Event 2, Berlin

3.2.3 Case study 3: Understanding gene expression

Again, this case study mentions a clear benefit for people. It supports the healing of an illness, in this case a kidney disease. This had a strong impact on participant's support for this area of research. Participants questioned whether this technology can also be used to prevent getting this illness. The fact that scientists use zebrafish drove curiosity. It triggered a discussion around animal testing, which evoked concerns among some people.

"On the positive side is that the disease can possibly be cured. The animal experiments are negative."
Event 2, Berlin

The fact the animal being used here – the zebrafish – is such a small animal, made the negative of animal testing more acceptable. Explanations on how and when these fishes are used were interesting for most. It also triggered a question about how the test setup with zebrafish looks. Most participants were amazed that it is possible to draw reliable conclusions from this research, and the knowledge that there is a link between fish and human beings.

3.2.4 Case study 4: Editing model organisms

The strongest support for genome editing was triggered by this last case study as it is research that is contributing to attempts to cure one of the most aggressive forms of cancer. It evoked a strong personal attachment given how common cancer is and how it affects most families. Support was also strong as the research is targeted, which means that less harm is done to animals as the experiment has a clear objective and focus. Some participants asked whether animal testing would cease to be needed. They were wondering if an organism and its reactions can be copied by computer modelling, which could then run the experiment only in a digital way, without the need for animals. A discussion around animal testing was triggered. Insights given by the experts on how, when and under which limitations animal testing is allowed were helpful for participants to further accept the use of animals in scientific research.

"I think it is very positive that research is being carried out, meaning that cancer cells are being produced and implanted in mice. There is no other way to achieve a result. You can't try it on humans. If you want to make progress in science, such experiments are indispensable."
Event 2, Berlin

3.3 Views of different groups and how they differ

Please note that since the groups were not split into different segments of the population, differences between target groups are only indicative.

- Participants with higher levels of educational attainment appeared to have a higher awareness of ethical debate and understanding of genome editing.
- Women and men looked at genome editing from different points of view. Men assessed genome editing as a technological advancement and appeared somewhat more interested in the technical advancement. Women on the other hand tended to be more interested in the potential to improve quality of life through genome editing.
- There were not many participants who were completely against genome editing and its research applications. However, older participants appeared to be slightly more concerned and worried about the possible unintended drawbacks.

3.4 Implications for MDC

Awareness and understanding of basic research was low, therefore participants tended to have a lot of questions when presented with the case studies of MDC's research. Once they did have a better understanding of these, they were positive and hopeful about the potential of the technology, specifically in relation to medical developments. Therefore, it will be important for MDC to communicate clearly about what they will be likely to achieve with the technology in the near future, in order to manage expectations around this.

Participants did also have concerns about potential negative implications of the technology such as ensuring equality of access and limiting unintended effects so it will also be important to make sure that protections and regulations around the technology are clearly communicated.

4 Views of possible future uses of genome editing

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

- Genome editing for medical purposes – genome editing techniques might be able to help tackle diseases, through the use of non-heritable genome editing as well as heritable genome editing. Experts involved in the discussions also introduced the idea of new treatments such as gene therapies, which are taking place in clinical trials[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 Germany.[14] 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.[15]
- Genome editing for human traits – the idea that in the future, genome editing could enhance human traits such as intelligence or endurance, as well as cosmetic traits such as hair or eye colour.
- Genome editing for animals and livestock – genome editing could make animals more resistant to disease, and enable more sustainable farming practices.
    - As part of this case study we also spoke about the possibilities of editing the genomes of insects such as mosquitoes to inhibit their ability to develop and spread malaria, thus potentially bringing about medical benefits.

[13] https://www.discovermagazine.com/health/gene-therapies-make-it-to-clinical-trials
[14] https://www.ethikrat.org/fileadmin/PDF-Dateien/Veranstaltungen/trilaterales-treffen-21-10-2016-merkel.pdf
[15] 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 Ipsos Germany 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 B. These handouts were designed to enable participants to reach some conclusions on acceptable uses and what trade-offs, and under which circumstances, they are willing to make. The experts supported these discussions by answering questions, speaking about research using genome editing, and giving balanced information about possible benefits and negative consequences.

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

4.1 Overall acceptability of different uses of genome editing

To gain an overall understanding on the impact of each future possibility, the possibilities discussed are presented here by order of acceptability.

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

Although using somatic genome editing (changes that will not be inherited in the embryo) in humans for medical purposes was not the preferred choice in the beginning of the discussion (as it was viewed as less efficient than germline genome editing for medical purposes where changes will be passed on to the progeny), when discussing the issue in detail, participants thought this type of genome editing in humans offers many benefits.

For example, that the impact of using somatic genome editing techniques is reduced compared to germline genome editing as faulty genes are edited in a way that is not passed on through generations. The results will be confined within the human who has had their genome edited. Unknown, negative effects will therefore be limited by not being able to be passed on genetically, which gave participants the feeling that one can broaden knowledge in the area of genome editing while at the same time having a stronger control over the situation.

As the outcome is somehow unclear and cannot be predicted, participants felt that somatic genome editing is more responsible, given it is the person who decides to use it for themselves, and does not make that choice for possible future generations.

Aspects of control and safety were of paramount importance for participants. The technology is rather new and very complex. Encouraging the use of somatic, rather than germline, genome editing techniques reduces concerns about problematic unintended consequences that would be passed on through generations. The complexity of this technology was also overwhelming for some people. Those who had not heard or read about this topic beforehand sometimes had a hard time to process all the information and to form a strong opinion straight away.

"I'm just noticing that I'm totally overwhelmed because I keep coming back to the same point. I can't position myself 100 percent on this."
Event 2, Berlin

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

Many participants saw the potential to eradicate diseases using genome editing technology as a great opportunity and preferred the use of germline genome editing for this purpose over using somatic genome editing for medical purposes at first glance. However, this changed over the discussion and by gaining more insights into the current state of research, and there were also questions around how it would work in practice, and the technical aspects of the technology were not understood at first (e.g. difference between somatic and germline genome editing).

The highest relevance and acceptance was distinct – when illnesses are caused by a genetic defect. Giving people the chance to have children on their own without having to fear that a genetic defect is passed on to their children was regarded as a means of equality. In these cases, germline genome editing was highly accepted among participants. Acceptance was also high if the technology could be used to help treat a severe illness, such as cancer.

"If cancer occurs very often, I think it's great not to have to pass it on to your children. People might want to have children anyway. And there are other genetic defects and not just cancer. It opens up many possibilities. The topic touched me directly with having children."
Event 2, Berlin

However, the more participants discussed the topic, the more the trade-offs and questions became obvious to them. Prevalent drawbacks of the use of germline genome editing in humans became more obvious:

1. The impact of using the technology in this way is much greater, as editing reproductive cells and early stage embryos is changing the genes passed on to future generations. Participants were particularly critical of using genome editing technology to edit humans for medical purposes when this intervention has unknown, unintended consequences.

2. The implication of this form of genome editing for others (future generations) was also seen as rather negative. Participants preferred to limit decisions about whether or not to use genome editing for medical purposes to the individual.

3. **It was also regarded as a shortcut to a standardised human society in which disabilities are not accepted anymore, where everyone who is out of the norm will not be an equal part of society anymore.** In Germany, historical comparisons were made, especially in regard to the 3rd Reich, where a regime of eugenics was used to try to create a 'better and superior' race. This was strongly rejected, and fears were triggered that this new technology could lead the way to such negative societal developments.

4. **The potential of overpopulation was regarded as an issue by participants. Germline genome editing provokes the idea that everyone is healthy and lives a long life.** That triggered a conflict with the current perceived issues of overpopulation. Participants were worried that inequality will increase, and only rich people will get access to treatment and be able to live longer. The current divide between rich and poor could widen.

5. **Before germline genome editing in humans is legal, participants felt there should be an international convention agreed to regulate the use of it.** Also, public education is required to fight prejudices against minority groups.

Comparing and trading-off somatic and germline genome editing for medical purposes:

The possibility that genome editing technology has the potential to treat disease by changing 'faulty' genes was regarded as a breakthrough and as potentially having a direct beneficial impact on peoples' lives. For many participants, this was a new and unknown possibility and it gave hope that genome editing can reduce hereditary diseases. Treatments around the following illnesses were spontaneously mentioned and discussed:

- Illnesses/disorders caused by a genetic defect e.g. dwarfism, deafness
- Cancer
- HIV
- Alopecia/hair loss
- Allergies

However, the more participants discussed somatic and germline genome editing for medical purposes, the more the trade-offs and questions became obvious to them:

1. **How acceptable is it for humans to be allowed to erase illnesses/disorders completely?** The tension that was discussed was that each individual's degree of suffering is different, even if they are in the same circumstance. One person might feel as though they are suffering from their hair loss/deafness, but another person with the same condition might not.

2. **Who should be allowed to decide what are acceptable uses of genome editing, and how an illness/disorder will be treated?** For participants, the individual's choice to get treatment was the highest priority. However, they recognised that with ongoing research and an incorporation of the technology into the public health system, other players will gain more power over how the technology is used. For example, the state and health insurance companies. This made people

question whether they would still be able to decide for themselves, if the state and the health insurance system will not support welfare benefits/treatment for certain hereditary diseases anymore.

3. Will economic interests and the greed for profit lead to an even more inequal society? Participants feared that enterprises will limit the access to these new forms of treatment by putting a high price tag on it.

"The legislator can say, why don't you do that, we'll cancel your benefits. Many disabled people get benefits from the state. Then the legislator must decide on this operation. Only healthy and strong people will survive (...) Joy and fear at the same time."
Event 2, Berlin

All of these trade-offs led to the thought that a fundamental debate is needed on how to handle these new treatment possibilities which use genome editing. It is important that this includes talking to organisations which represent people affected by conditions that genome editing could address, e.g. the association of deaf people.

It was obvious to participants that for now, genome editing technology should only be used to cure of prevent an illness to relieve people from suffering. Right now, the use of genome editing technology for medicinal purposes should not go beyond this aim. It was felt that genome editing technology should only be used to prevent an inheritable disease when it is certain to occur in an individual; using genome editing technology on individuals for whom a disease might or might not develop (for example, genes that may increase the risk of contracting a disease but not cause it with certainty) was less accepted because the risks of unintended effects are difficult to determine right now and might have long-term, uncontrollable effects.

Many trade-offs came into play when participants thought thoroughly about using genome editing for medical purposes. The following aspects are relevant when deciding on the use of somatic genome editing compared with germline genome editing in humans:

1. Impact level: Firstly, this is the main trade-off – how far-reaching is the impact of the genome editing? Right now, options that minimise impact level (i.e. somatic genome editing) are preferred. Currently options that minimise all impacts (both positive and negative) are preferred while there are still many unknown and unintended consequences from the use of genome editing technology.

2. Costs: How much does using the technology cost and how much money could be saved? This was seen as an argument for the use of germline genome editing in the long run (as it could save more money than using somatic genome editing at every generation), but the negative and unknown consequences of using germline genome editing were weighted stronger than this perceived benefit.

3. Geographical location and economic situation: These aspects were considered to have an influence on decisions around whether germline or somatic genome editing is appropriate. For example, there might be circumstances in developing countries where the benefits of using germline genome editing outweigh the drawbacks, and then it might be justified to use it.

"[On comparing somatic vs. germline genome editing] It depends on where that is. In Africa there are tens of millions of people with HIV. We would have to take a different approach than in our industrialised countries. Women are abused (...). We have to apply different standards in order to give these countries a future."
Event 2, Berlin

To enable people to make fully informed decisions about the use of the technology for medical purposes, participants also wanted to know:

- What impact does germline genome editing have on the immune system? The experts mentioned that regarding the case of He Jiankui purportedly editing the genomes of twin babies, this genome editing may have had unknown effects on their immune systems.
- What is the difference to current treatment with medication? There are presumably side effects with either option.
- Who is responsible for possible negative outcomes as a result of genome editing when it is done on humans? The doctor? The patient? The state?
- How strongly will enterprises have a say in how the technology is used?

4.1.3 Views of genome editing animals and livestock

The cases around genome editing animals were highly controversial. Two aspects in particular provoked a debate:

1. The aspect of environmentally sustainable farming was not understood by participants. It did not seem sustainable when animals are edited in such a way that they may need less space or require less feed.

It raised concerns that profits could get even more in the way of animal welfare than is already the case today. Respect for animals may be undermined even more.

There were also concerns that genome editing could result in unintended changes to animals. Participants mentioned that currently, selective breeding can also support changes that are detrimental for the animal itself. Examples of overbreeding amongst dogs were given.

Furthermore, there were perceptions that genome editing does not address the roots of the problem. Participants felt that debate on lifestyle change to take environmental and climate issues into consideration would be more helpful.

"People are lazy. If we can change everything through genome editing, then we have no motivation at all to change our behaviour."
Event 2, Berlin

2. The fact that pig organs will be used in human transplants in the next five years raised aversion from some participants: Firstly, because an animal organ would be part of the human body and secondly because pigs would be killed for this use.

Further thought on this issue limited this aversion, as intensive livestock farming was seen as more problematic, and because participants were already aware of examples of animal organs, such as calves' livers, being used for medical purposes. In general, it was accepted. **Again, one can conclude that the aspect of health supporting human life is a big driver in reducing concerns.**

The debate also triggered questions that seem unanswered thus people needed further information on:

- What happens when humans eat meat from animals that have had their genomes edited? What is the impact for human beings?
- Is it really possible to make chickens resistant to bird flu given the virus changes every year?

4.1.4 Views of genome editing plants and crops

Germany is a country with low prices when it comes to food. The possibility that food might not be as accessible to other countries or that it might not be as accessible in Germany anymore in the future because of climate change was hard to imagine for most participants. This reduced the perception of relevance for genome editing plants and crops. Concerns were more prevalent:

- Again, participants argued that using genome editing to improve crops does not address the roots of the problem. A debate on lifestyle change that takes environmental and climate issues into consideration was seen as being more helpful.
- Participants also feared that powerful companies, such as Monsanto, will use this technology for their own good without taking people's concerns into consideration. This would create a dependence on these companies. There were concerns that a greed for profit would limit the possible positive uses of the technology for plants.

Besides these concerns, **some mentioned that the genome editing of crops might be a necessary solution for crisis areas where climate change has the largest negative effects.** Participants were more willing to accept the usage of genome editing in such contexts.

"When I think of drought and floods, I can imagine that some problems can be solved worldwide with them."
Event 2, Berlin

Participants still had several questions concerning genome editing on plants:

- What is the impact of eating genome-edited plants on human beings? Are there side effects, and what are these?

- What might be the dangers associated with the introduction of edited plants into the natural eco system? (not everyone was aware of problems).

When it came to their own consumption, increasing the nutrient level of a plant was acceptable, as long as it only increased nutrients that are a natural part of the plant. Gluten-free wheat and altered taste were not seen as being as relevant. People were concerned that allergy sufferers might not be able to detect allergic substances in food anymore if alien material were introduced when manipulating a plant. However, this type of genetic manipulation was deemed more acceptable for use in regions where there is a food crisis, to be able to provide people with all the nutrients they need.

4.1.5 Views on heritable genome editing for non-medical purposes

The idea of editing genomes for cosmetic uses or enhancement was outside of people's everyday life and provoked concern. Editing human traits was therefore viewed as being unnatural and not furthering the aim of healing and relief from suffering. It was seen as the base for inequality, where money will be even more dominant and influential as access to this technology will be controlled by it. This also triggered fears and concerns of:

1. A society where everyone will be physically the same.
2. A society that strengthens a wealthy elite who can afford to use the technology.
3. A society that tries to create a "better" and "superior" race (the link to 3rd Reich was prevalent here).

"There's Super Man. It's like nuclear fission. First positive and then we have the atomic bomb. This research should be limited to diseases."
Event 2, Berlin

"An athlete runs the 100m in five seconds. This is a catastrophe. In terms of sport, there should be no superhumans. It would destroy a lot."
Event 2, Berlin

The possible drawbacks of using genome editing for human enhancement were seen as much stronger than any possible benefits. There was also a perception of a 'ladder effect', that accepting to alter single human traits will pave the way to alter whole human beings. It was regarded as a vicious circle that cannot be stopped anymore once this limit of acceptability is crossed. Strong international regulations would be needed to prevent abuse of the technology for these purposes. The aspect of work-related benefits was also not sufficient for most participants, as human shortcomings can be overcome by technologies such as machines etc.

4.2 Implications for MDC

The following aspects should be taken into consideration in light of participant views on the possible future uses of genome editing. It was discussed that it is important for MDC to be transparent about the research they do. If the public have a clearer understanding of how scientists conduct research with genome editing techniques this increases public trust. This includes being clear on the range of areas that this research using

the technology is conducted, including on humans, plants, and animals, **and why it is important that research is done in these areas**; the reasons are not necessarily obvious or understood by everyone. Transparency is also increased through **talking about both the benefits and the drawbacks of the technology, and presenting differing perspectives**. This also makes it easier for the public to get an idea, and make their own judgements, about the potential impact of this technology on society.

Genome editing applications were seen as having great potential for bringing benefits to society; however the public still have many questions, which are stated throughout this chapter, as to how it will be used in practice. **MDC researchers may not yet know the answers to all these questions, but as the role of the technology becomes clearer it will be important to keep the public informed and try to address these**.

Editing human genomes for medical purposes in particular is viewed as having great possible benefits but also needs to be handled with great care as the possibilities become reality in order to avoid harm. **MDC should endeavour to involve representative/advocacy groups in conversations about potential research uses.**

Finally, **it is important that MDC is seen as being involved in and promoting international regulations for genome editing technology**. This is because people are concerned that it might be possible to lose control over how this technology is used, and clear regulations would be the best way to help allay some of these concerns. Participants thought that MDC representatives could sit on a type of committee that makes decisions on international regulations of the technology – it was felt that this involvement in setting international regulations could help to prevent misuse of the technology by other individuals or organisations.

5 Communication and engagement

A key objective of this public dialogue for MDC 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 MDC 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'[16] created for the purpose of these public dialogue, in collaboration with artist Emilia Tikka and MDC, and were asked to reflect on it.

5.1 Communications context

As an ORION partner, MDC is already committed to being accessible, open and transparent with members of the public. As part of this commitment it has been developing training resources for researchers about Open Science, including developing workshops, podcasts, videos, booklets and online platforms.[17]

ÆON, the art piece shown during the public dialogue events for this project in all four countries, was developed in collaboration with MDC scientists. The artist, Emilia Tikka worked within MDC's laboratories for two months conducting research into the CRISPR/Cas9 genome editing technique and developing the artwork based on this. *ÆON* has been exhibited at the MDC before, prior to it being used in this project.

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

Participants viewed genome editing technology with respect. It opens the door to many possibilities, some of which are good, others potentially harmful. Nevertheless, there was a positive attitude towards it because of a perception that science means progress. It was discussed that the public trusts science and scientists. This means that the public accepts that research outcomes are not clear from the start. There was a strong belief that scientists and high ethical and regulatory standards will make sure the effect of genome editing on humans will be safe.

"I don't know whether new aspirin has other adverse effects than those on the patient information leaflet. You have to have faith."
Event 2, Berlin

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.

[16] https://www.emiliatikka.com/new-page-1
[17] https://www.mdc-berlin.de/orion-open-science

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

Participants recognised that they did not have enough understanding and knowledge to understand everything to do with genome editing. Nevertheless, they called for transparent and accessible information on the genome editing research that is being done. The institute's website should accordingly provide this information. This includes both information about the technology and the implications of using genome editing technology. The former, about the technology, is more interesting to those who already have a greater understanding and interest in the subject. They believed that the more information can be provided, the better.

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

Participants reported trust in scientists because they are experts in their field, and it was felt that clear communications to the general public reaffirmed this trust. Trust originates from an understanding of why scientists conduct research using genome editing techniques. The "why" is answered by an understanding of the implications of genome editing – how it may impact the publics' lives, and the values that underpin the work of the scientists using these techniques.

Knowing and understanding scientists' values would diffuse worries about the potential harm genome editing could do. Because there are possibilities for the use of genome editing technology to have negative consequences, participants were concerned that private companies could act against the publics' best interest. Highlighting the regulatory European framework within which MDC operates could also help to build public confidence. Understanding the values of scientists and the boundaries within which they operate would further enhance trust that ethical boundaries and the public good are central to their work. Values of scientists that should be communicated include a sense of responsibility and interest in the public good as well as being grounded in ethical values.

"[It is important to know their values] so that you know they do not just do it to make money, to register patents. But that they do their work because they believe in it, that the believe in helping people."
Event 2, Berlin

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

Implications of genome editing should be communicated transparently and in a way that is easily understood. To participants, transparency means communicating both negative and positive implications. On the one hand, this will enable the public to form their own opinion on genome editing technology and whether the 'good' outweighs the 'bad'. On the other hand, the public want to hear from scientists around why they believe genome editing technology should be used. This is particularly the case when it comes to the potential of genome editing in humans for medical treatment.

"The more information you provide, the less speculation."
Event 2, Berlin

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

In summary, genome editing is considered of importance for the entire public, hence everyone should be able to form an opinion on the subject. Currently knowledge on genome editing is not widespread and the public has many questions about it. This means **communication on genome editing needs to be easily understood and accessible.** The need for simplicity, wide reach and the opportunity to ask questions as part of communication about genome editing technology is reflected in the preferred communication approaches (discussed in the following section).

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

The dialogue suggests that once informed, the public understands the wide-reaching potential impact of genome editing technology. Like climate change, it is a topic that could affect everyone. Therefore, participants considered widespread education about genome editing important and **thought it should be included within school curricula** (it is already included in the school curricula in Germany).

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

- Animated videos
- Videos of scientists talking about their work
- Television
- Academic journals
- The MDC website
- Social media
- Citizen science
- Citizen's forums
- Printed media
- Public Science fairs

- Exhibitions showing the technology and Open Days
- Theatrical performances

Participants felt communications about genome editing first and foremost need to reach a broad spectrum of society and in a second step communication can become more specific and filter down to more specialised content. TV and social media were the two key means to reach the wider public. TV was more popular as a channel with the older demographic (above 45), but both were considered as important to raise awareness about genome editing and create some basic understanding.

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

Video content was also a clear favourite for communication. Animated videos, e.g. on YouTube, felt like a very promising tool to communicate the complexities of genome editing technology. Animation was greatly liked, because through visualisation complex concepts could be simplified. It was also liked because it engages different learning types (listening and seeing). Furthermore, animated videos can be utilised in schools to help increase education on genome editing from a young age.

Video content that includes scientists themselves was another favourite. Since it was established that the values of scientists play an important role in building trust, participants believed that scientists should talk about their work on TV or in videos on social media (or embedded videos on the MDCs website). Scientists contribute respectability to genome editing and increase trustworthiness. Because of that, they should also be included in discussions on TV with other stakeholders.

The opportunity to ask questions is very important to the public. For one, the complexity of the subject means that the public want reassurance. Secondly, opportunities for questions make the public feel engaged, which reduces fear about genome editing. Open days are known as a format for this and were thus liked. Citizen Science as a format is not widely known but raised interest among participants. Both were liked because of the increased engagement through personal contact. The only downside was that public formats tend to be used by people who already have some interest and knowledge, hence these formats were not considered as sufficient on their own.

"By being able to engage, you can get more information. You also have the feeling that you are a part of it, this provides you with a different conscious for the subject."
Event 2, Berlin

Participants of the public dialogue felt that they greatly benefited from being involved in this experience. It was liked because scientists were able to answer questions, making science and genome editing more accessible. The format enabled participants to gain a perspective on the positives and negatives and thus benefited participants to develop a nuanced understanding of genome editing. Furthermore, participants felt dialogues reduce the possibility for false or misunderstood information. However, the format was recognised to have limited reach compared to other formats and relatively high cost too. Public dialogues are greatly beneficial to those participating, but difficult to increase their impact beyond the people directly present.

Participants liked the dialogue format because they could make themselves heard. They thus believed that the public dialogue presented an opportunity for scientists to hear what different types of people think and adjust their communication accordingly.

Therefore, a communications strategy should make sure that the style is simple, has wide reach across all spectrums of society and needs to include events where the public can engage into a dialogue with scientists, and specifically in relation to:

- The MDC website: The foundation for such a strategy should be the website of MDC. Since the public considers transparency of information as highly important, the website should communicate what research is being conducted using genome editing technology and offer the possibility for further information and academic papers.

- Linking the website to other communication channels: Ideally, the website will link to further communication channels, such as videos, social media, and opportunities for engaging with the scientists themselves, e.g. events such as the Berlin Science Week. Using a portfolio of different communication channels can aid comprehension and expand reach. Since people learn differently and have different media consumption habits, a communication strategy needs to be built on different pillars, e.g. video content and articles.

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

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

Method	Pros	Cons
Animated videos	Can portray complex information in simple ways Engages different learning types (listening and seeing) Suitable for children (could be used in schools)	Limited knowledge transfer
Videos of scientists talking about their work	Increases trust and respectability as a real scientist gives insights	Risk of scientists using overly complex or language that is too technical for the public

		Might be too one sided
Television	Has a wide reach	However, one should consider documentaries on streaming providers such as Netflix as well as not everyone watches standard TV anymore
Academic journals	Specific knowledge	Reach is limited, as it has a too specific target group, especially people with a non-academic background find it too specific and fear problems of understanding
The MDC website	Can link to other online resources	Reach is limited as website is not known by many
Social media	Inexpensive Has a wide reach Post can be very diverse: articles, videos, etc…	Making sure that credible sources are used
Citizen science	Engages and involves the public directly and the personal nature of this method would increase engagement	Would tend to be used by people who already have some interest and knowledge – limited reach
Citizen's forums (such as dialogues, juries, and assemblies)	Able to talk to experts, which benefits both the public and the experts Complex information can be understood – enough time is given to talk about the issues (and discuss pros and cons) Reduce the possibility for false or misunderstood information. Public can express their opinions to the scientists, and challenge them	Very limited reach – difficult to increase their impact beyond the people directly present Expensive method

Printed media	Can have a good reach when it is published in a national newspaper (especially as these newspapers have an online appearance as well)	Some only use print media on local level
Public Science festivals	Can be interesting day when fair is also suitable for children	Would tend to be used by people who already have some interest and knowledge – limited reach
Exhibitions showing the technology and Open Days	Gives people the opportunity to ask questions Personal nature of this method would increase engagement	Would tend to be used by people who already have some interest and knowledge – limited reach
Theatrical performances	Gives people the opportunity to ask questions and to engage in critical thinking	Limited reach, too abstract for many

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

One of the ways the MDC has communicated its work is through the means of art. 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 MDC. Emilia Tikka, an artist, designer and PhD candidate at Aalto University, The School of Arts, Design and Architecture in Helsinki, won the bid with her work entitled '*AEON Trajectories of longevity and CRISPR*'. Images of the artwork can be found on Emilia Tikka's website.[18] 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.

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

Figure 5.1: Images of AEON Trajectories of longevity and CRISPR

One of the aims of the art piece was to provoke discussion around the issues arising from a potential future use of genome editing technology. The art piece successfully managed to provoke this discussion and led participants to reflect about ethical challenges that might arise from genome editing in order to prolong healthy ageing. Key themes that were discussed included the risk of overpopulation vs. fulfilling one's individual desire to live forever; health of body vs. mind; loneliness, and the possibility to divide society along the lines of opponents and proponents of using the technology to prolong life.

"I have realised, that society will drift apart [when we individually can decide to use genome editing to prolong life]. This causes chaos. I can imagine that social order and appreciation are lost."
Event 2, Berlin

Overall, the art piece thus fulfilled its purpose, because it left room for interpretation and encouraged people to think about the reasons why the artist chose to present the technology in that way.

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

The piece sparked particularly intense debate because it led participants to choose sides: would I have been an opponent or proponent of using the technology in this way? Participants who in previous discussion had primarily seen the advantages of genome editing suddenly felt uncomfortable. These participants critiqued the piece for being too negative and reflecting the views of someone who is an opponent of genome editing. At the same time, there was a perception that a positive portrayal would not have provoked discussion or led to more nuanced views. The art piece successfully enabled participants to reflect the implications of a future where genome editing to prolong life is possible, because it challenged their existing views.

The extent to which the art piece can provoke ethical discussions outside of a moderated dialogue with additional information is unclear. It is important to note that the role of genome editing technology within the art piece was not fully understood. The extent to which the public could understand that the art piece is about genome editing without the explanation given upfront by MDC and the information provided about it (Appendix C) cannot be said for certain.

6 Conclusions & Recommendations

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

Table 6.1: Table of conclusions & recommendations

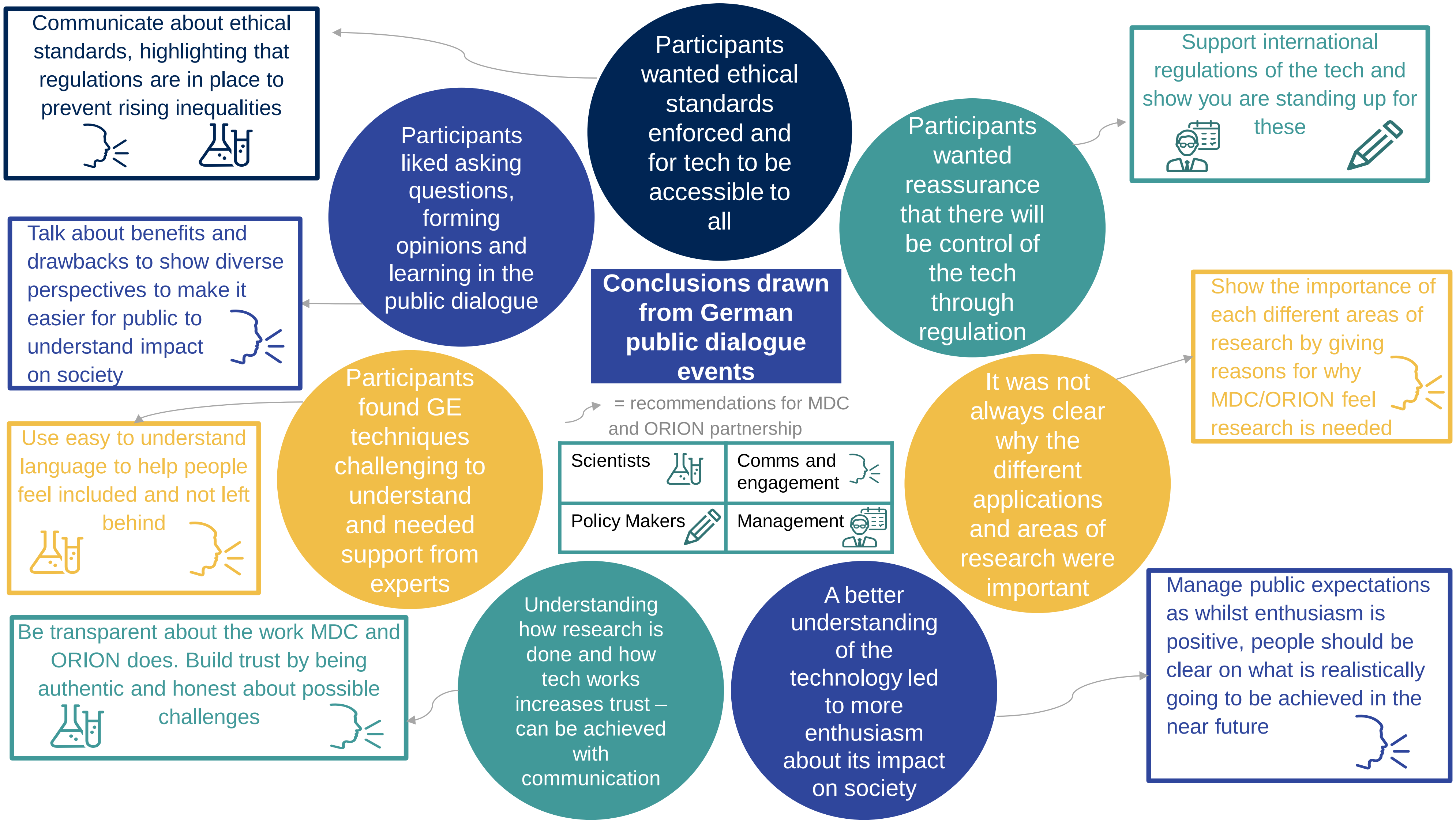
	Conclusions	Recommendations	Recommendation for:
1	Participants liked the format of the public dialogue workshops as they could ask questions about the technology and form their own opinions on it. This approach allowed them to gain a better understanding of the technology.	Talk about benefits and drawbacks: always show diverse perspectives to make it easier for the public to get an idea on the impact to society and to educate people.	• Communication and engagement specialists should communicate about the possible risks as well as benefits of the technology
2	Genome editing techniques are complex and were challenging for people to understand (without seeking clarification from experts participating in the dialogue). This complexity can be intimidating for people.	Use easy to understand language: using easy language lets people feel included and not left behind in a discussion (especially those with no academic background).	• Communication and engagement specialists should ensure public-facing materials use easy to understand language • Scientists should also ensure they use easily understood language when communicating with the public about their work
3	Having a clearer understanding of how research is done and how the technology works would make people more trusting of this technology, one way to ensure this is	Be transparent about work done in MDC and ORION open science: showing people how scientists conduct research. Be authentic and honest: based on the need for an authentic and honest communication one role of	• Scientists should be at the forefront of communicating about the technology, as this will ensure authenticity of messages and can help to build trust • Communication and engagement specialists may

	through clear communications.	the MDC is to address ethical challenges. This should be prominently featured in communication about genome editing. The key for a successful communication strategy is to find a balance between staying authentic to build trust (hence do not use spokespersons who are not scientists), and simplistic without sugar-coating possible ethical challenges ahead.	need to provide support to help scientists to do this
4	Once participants had a better understanding of the technology, they were enthusiastic about the impact it could have in society.	**Manage public expectations:** this enthusiasm is a positive sign of how people will respond to future communications around genome editing. However, it will be important that people are also clear of what is likely to be achieved with the technology in the near future.	• **Communication and engagement specialists** will need to take public expectations into account in how they communicate about the technology
5	It was not always immediately clear to participants why these different applications and areas of research were important.	**Show the importance of each different areas of research:** mention the reasons why MDC / ORION feel research in different areas such as research using genome editing with animals or humans is needed.	• **Communication and engagement specialists** can outline why research is being conducted in these different areas
6	Participants wanted reassurance that there will be control of how the technology would be used in the future through regulation, and reassurance that there would be measures in place to prevent abuse of	**Support international regulations around the technology:** MDC and ORION open science should be shown standing up for these.	• **Management within the ORION partners** should demonstrate support for international regulations of the technology. It may be necessary to engage **Policy Makers** when doing this

	such an impactful technology.		
7	People also wanted assurances that ethical standards exist, what they are and what is being done to regulate them. This included understanding of what will be done to ensure and prevent inequality in terms of access to the technology.	**Communicate about ethical standards**: This should be done whilst also highlighting that the application of **genome editing is internationally regulated to defeat fears that inequality will rise on an international level.**	• **Communication and engagement specialists** should be clear about the ethical standards and regulations the technology is currently held to, to prevent fears over misuse of the technology • **Scientists** can ensure they include ethical standards and regulations when they communicate about their research

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: Case studies shown to participants

Converting skin cells into egg cells

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

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

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

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

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

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

Ipsos MORI
Social Research Institute

17

How does titin affect heart growth

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

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

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

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

Ipsos MORI
Social Research Institute

18

Understanding gene expression

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

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

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

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

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

Ipsos MORI
Social Research Institute

19

Editing model organisms

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

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

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

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

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

Ipsos MORI
Social Research Institute

20

Appendix B: Future possibilities of genome editing handouts

Future possibility 1:
Genome editing for medical purposes

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

Ipsos MORI
Social Research Institute

13

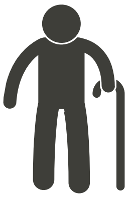
Future possibility 1:
Genome editing human embryos

- 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.

14

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**



Ipsos MORI
Social Research Institute

15

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

16

Future possibility 4: Genome editing plants & crops

- GE could possibly be used to edit the genes of crops, to **improve taste, shelf-life, resistance to disease.**
  - Some people get sick when they eat food with gluten in, like wheat. Wheat could be genome edited to be gluten-free
  - GE bananas could be more resistant to a damaging fungus
  - GE pineapples (pink-flesh) or tomatoes (purple skin) have health benefits e.g. higher concentration of antioxidants. Where do we draw the line with cosmetic vs health benefits?

- With climate change, GE plants or crops might **cope better with rising temperatures or could survive in flood water**

- **GE crops / plants to make them more nutritious.** Some are concerned about introducing these GE crops into 'natural' ecosystems

Appendix C: Information shown about the art piece

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

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

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

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

Appendix D: Glossary of Terms

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

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

Appendix E: Advisory Group & 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[19]	The Babraham Institute (UK)	Director
ORION staff leading this project at participating organisations members of the Advisory Board:		
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)

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

German Review Group members

Senior member of Scientific Directorate Office, MDC
Senior member of Communications, MDC
Sandra Krull, Head of Postdoc Office, MDC
Jean-Yves Tano, Scientific Coordinator and Senior Postdoc, MDC
Luiza Bengtsson, Public Engagement and Knowledge Exchange Officer, MDC

Appendix F: 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[20]	The Babraham Institute	Public Engagement ORION Open Science Project Officer (maternity cover)
Tacita Croucher	The Babraham Institute	Public Engagement Manager
Hayley McCulloch[20]	The Babraham Institute	Public Engagement and Knowledge Exchange Manager

Ipsos project team

Name	Organisation	Role
Michelle Mackie	Ipsos MORI	Research Director and Head of Ipsos Dialogue
Graham Bukowski[20]	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

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

Hans-Juergen Friess	Ipsos Germany	Director
Katja Kiefer	Ipsos Germany	Senior Research Executive
Laura Wolfs	Ipsos Germany	Senior Research Executive

For more information

3 Thomas More Square
London
E1W 1YW

t: +44 (0)20 3059 5000

www.ipsos-mori.com
http://twitter.com/IpsosMORI

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.