Public dialogue on genome editing

Czech Republic country report

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

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We would also like to thank all of the stakeholders who participated in the stakeholder workshops and contributed to the development of the materials used in the public dialogues, as well as the experts who attended the public dialogue events and participated in discussions. The name of the stakeholders and experts who participated in the Czech events are listed in Appendices A and B.

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

Members of the Advisory Group and Czech Review Group who have agreed to be named in this report are listed in Appendix G. The Babraham Institute's Public Engagement Team and the Ipsos project team who contributed to this project are listed in Appendix H.

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

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

Executive summary

The ORION consortium[3] commissioned Ipsos MORI to conduct a series of public dialogues focused on the views and concerns of the public regarding the application and implications of using genome editing[4] technology in ORION research institutions. Events were held in four countries where ORION partner institutions are located; the UK, Germany, Sweden and the Czech Republic. **This report details findings from the dialogue held in Prague (Czech Republic).** During the events, members of the public discussed applications of genome editing techniques, possible future uses of the technology, and explored the best ways for the ORION partners to engage with the public about genome editing.

Views of key societal challenges and solutions

First, participants were invited to think about key challenges and problems currently facing society and how those challenges could be solved. **Disease, insufficient food for a growing population and environmental problems (global warming and climate change) were seen as some of the biggest problems.** Other challenges included population growth causing overcrowding, economic problems, addiction to technologies, lack of control of the internet and increasing stress leading to illness. While none of the participants mentioned genome editing technology as a solution, **science more broadly was viewed as a solution,** for example food shortages being tackled through producing genetically modified crops.

Views of basic research and genome editing techniques

While none of the participants (bar one) were previously aware of genome editing, they were initially positive and highly accepting towards genome editing technology, with great expectations that this technology may help to tackle problems such as combatting diseases. While they appreciated that certain genome editing techniques have become less expensive and more widely used by scientists, there was concern about what might happen if genome editing techniques like CRISPR Cas/9 were used in the interest of small groups as opposed to the benefit of wider society. **Participants assumed that basic research[5] and applied scientific research were closely linked**. Participants saw trial and error as part of the natural research process, and therefore showed **strong support for basic research**, even where it may not lead to applied outcomes.

Views of possible future uses of genome editing

Participants discussed a range of future possible uses of genome editing applications. **On the whole they agreed with the idea that somatic genome editing[6] for medical purposes could improve the lives of individuals with severe disease or a disability.** Genome editing of plants and crops did not appeal much to participants as it was not considered to be addressing vital issues – although participants could see the relevance of this use in

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

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

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

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

some cases. There was concern about genome editing livestock disturbing the food chain and interfering with existing ecosystems. Almost all participants rejected the current use of germline genome editing[7] in humans due to little knowledge of the biological response to this intervention. They were however, prepared to consider its use in the future because of its potential to tackle diseases. The overwhelming majority saw the use of genome editing to adjust humans' features as unnecessary and unnatural.

Communication and engagement

Participants were initially unsure of the best way that the ORION partners should communicate about their work to the public. **Participants advised not to go into too much detail about how the technology works because they thought many people would not understand it and could lose interest.** They **advised communicating about the successes and potential benefits of genome editing**. For example, they felt it would be effective to show examples of diseases that might be treated with genome editing technology, supplemented with stories of actual people benefitting from this treatment to make them more relatable.

Participants felt it was important to disseminate information about genome editing to the widest possible audience. Therefore, they emphasised television, which is traditionally considered to be the medium with broadest reach. Younger participants also suggested social media as a useful communication method. Animated videos, TV documentaries and public science events were considered to be effective formats for educating people. Other methods were considered to have limited appeal and likely to only reach those with an existing interest in science.

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 at provoking debate; discussion raised by the art-piece was heated and the art-piece was able to convey lots of information, and raise lots of questions, about the potential consequences of the use of genome editing technology.** However, participants needed clarification on the relationship between the main protagonists of the artwork. Without this explanation, some felt that the artwork could be interpreted as a story of a mother and her son, showing an ordinary life of these people. It also may only appeal to a small portion of society, namely those interested in art.

Key conclusions

In conclusion, information on the current position of science regarding genome editing and the potential of its use made people positive towards the technology. The discussions brought hope that the two biggest threats to society, diseases and shortage of food supplies for a growing population, can be solved using this technology. However, people also realised that there is potential for this technology to be abused by groups of people with certain interests, instead of being used for noble purposes. Participants realised that this is still a developing technology with potential adverse events that are not yet sufficiently researched. But, they were keen for the benefits that the technology has brought so far to be communicated to the widest possible audience, and considered televised approaches to be optimal in doing this.

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

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

1 Background, objectives, and method

1.1 Background

1.1.1 About ORION

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

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

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

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

Five Research Performing Organisations:

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

Two research funders:

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

Two research supporting organisations:

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

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

1.1.2 About this public dialogue

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

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

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

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

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

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

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

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

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

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

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

1.2 Aim and Objectives

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

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

Specifically, the dialogue sought the following objectives:

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

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

1.3 Method

The format of the dialogue within each country had important input from ORION participating organisations and their national stakeholders. These groups provided input into the materials in order to ensure they reflect

the genome editing research carried out by the participating research organisation and the national context of the use and regulation of genome editing within each country. In addition, scientists and other technical experts from each participating organisation and their networks joined in the dialogue events to provide specific knowledge and expertise.

The dialogue method used in the Czech Republic 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. Advisory Group membership consisted of international stakeholders with knowledge and expertise in genome editing, the ethical issues associated with the technology, and science communication, as well as senior management from each of the four ORION partners involved in the project. A list of Advisory Group members who have agreed to be named in this report can be found in Appendix G.

Review Group:

A Review Group was set up within each country to help frame the public dialogue materials to reflect the national and institutional context. The Czech Review Group membership consisted of staff from within CEITEC.

Ipsos Czech Republic & Ipsos MORI

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

CEITEC staff:

Staff within CEITEC liaised directly with Ipsos Czech, providing support at and introducing the events. CEITEC 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:

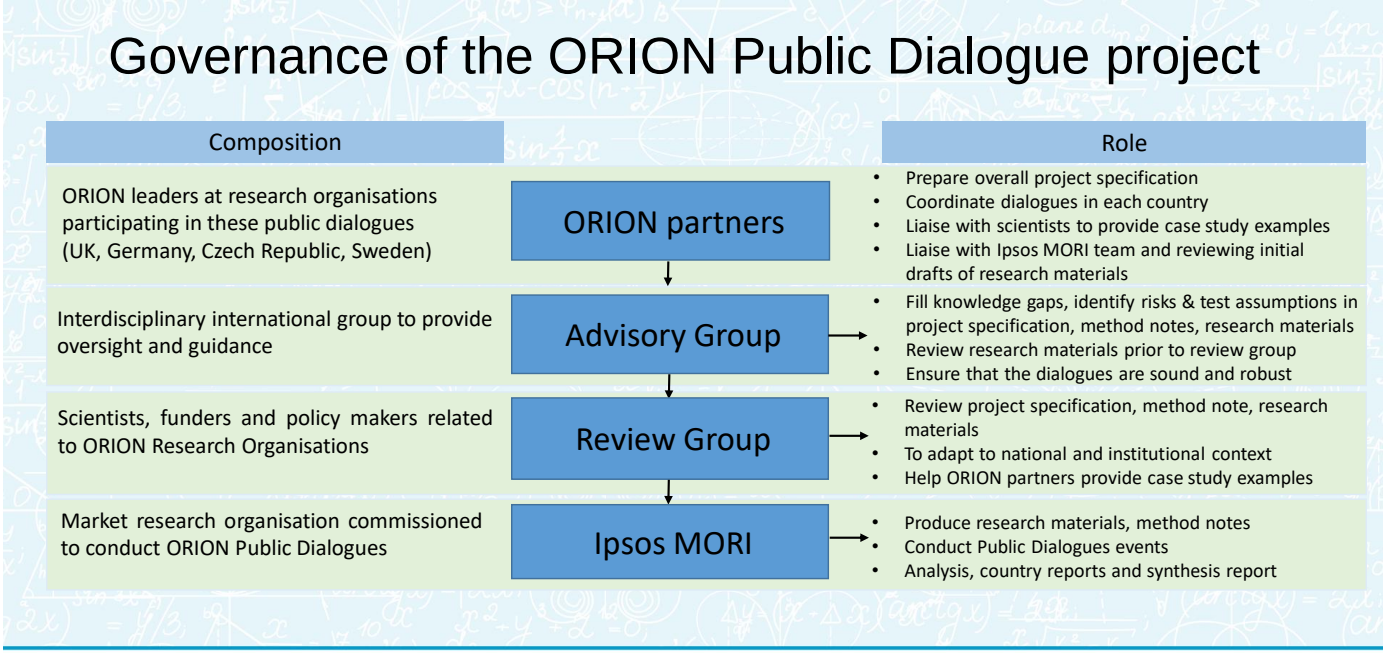
- Project specification – Initial document produced by the ORION consortium that outlined the background, context and rationale behind the project, the aims, objectives and proposed methods, the expected outputs and outcomes, anticipated risks, and proposed method of disseminating findings. It also outlined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

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 Ipsos Czech's offices with stakeholders including experts in genome editing, legal experts, research funders, a policy influencer and a journalist.

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

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

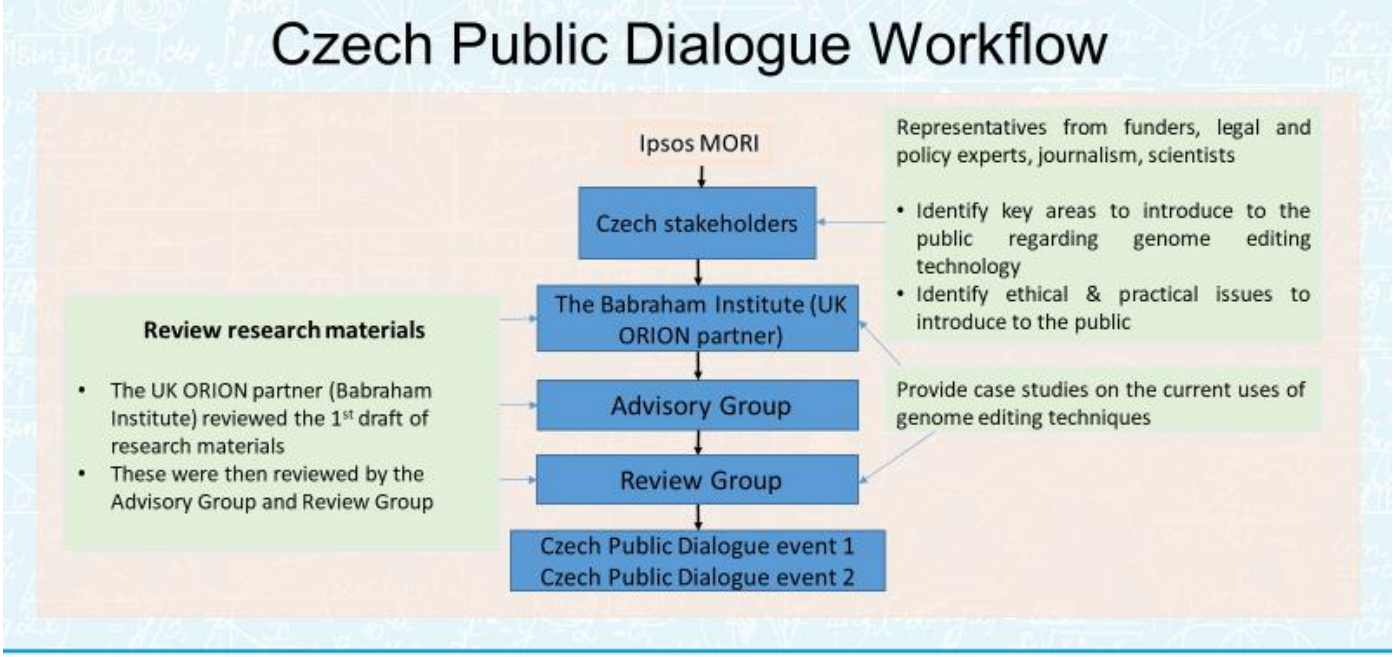
6. A pair of public dialogues were held with members of the public in Prague.

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

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

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

Figure 1.2: Workflow of the Czech Public Dialogues



1.3.3 Stakeholder workshop

A workshop with 12 of CEITEC's internal and external stakeholders (i.e. people with a vested interest in genome editing technology, some working at CEITEC and others working for other organisations) was held on 18th September 2019 at Ipsos Czech's offices in Prague. 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 CEITEC, in collaboration with Ipsos MORI and included a range of experts who brought different perspectives 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 Czech stakeholder workshop

Stakeholder Type	Stakeholder Sub-type	No. Stakeholders
Funders	Research funder	3
Experts in Life Sciences	Scientists in biology	5
Public Engagement Specialists & Journalists	Journalists oriented on science development, Czech public TV	1
Policy makers	Legal experts from the Ministry of the Environment and State Institute for Drug Control	2
	Policy influencer specialising in agriculture	1
Total number of Stakeholders: 12		

1.3.4 Public dialogue events:

Two dialogue events were held in Czech Republic with members of the public to discuss genome editing technology. Both took place at the Ipsos Offices, in Prague, Czech Republic. Thirty-two members of the public took part in both events.

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

Recruitment was conducted face-to-face in Prague. Recruiters approached members of the public and asked if they would be interested to participate in the research. If so, information would be provided to them on what the research was about and when and where the events were taking place. The recruiter would then ask questions using the screening questionnaire to collect information about participants. At this stage, participants were also given a privacy policy outlining who Ipsos and CEITEC 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 Czech public dialogue events

Social Grade	ABC1	15
	C2DE	17
Gender	Male	15
	Female	17
Age groups	18-30	8
	31-44	9
	45-64	9
	65+	6
Child status	Children at home	9
	Children sometimes at home	6
	Children have left home	9
	No children	8
Employment status	Employed	21
	Unemployed	11
Attitudes to genome editing before the events	Comfortable with the concept	16
	Uncomfortable with the concept	11
	Don't know	5
		Total number of Participants: 32

Participants were split into three discussion tables per event, with a good mix of 10/11 participants sitting on each table. Each participant was randomly allocated to a table, and sat in different groups at the two events.

Experts (people who have a vested interest in genome editing technology through their work, though not necessarily scientists using the technology) attended each of the events and were involved in the table discussions.

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

Experts were scientists identified by Ipsos Czech. Three experts attended the first event, and two of these attended the second event. A list of experts who attended the events and who have agreed to be named in this report can be found in Appendix B.

Event 1: The first event was an evening workshop that ran between 6.15pm and 9.15pm on Thursday 21st 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 techniques and the issues arising from it. Participants were informed about key biological concepts including DNA, genes, genome, and proteins, this enabled them to discuss different research uses of genome editing technology. Once participants had learnt about these biological concepts, they were shown and discussed case studies based on CEITEC's research using genome editing.

Event 2: The second event was a day-long workshop running between 10am and 4pm on Saturday 30th November 2019. During this event, case studies outlining examples of CEITEC's research were re-introduced to remind the participants about the type of research conducted by CEITEC, 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 possibility of this occurring was mitigated by:
  - Firstly, encouraging participants at the outset of the dialogue events to be open in their views and informing them that there were no 'right or wrong answers',
  - secondly, participants were invited to share their views directly with moderators prior to the experts answering questions or providing additional information,
  - thirdly, experts were provided with guidance about their role prior to the events, which asked them to play a neutral role in the discussions, not to take sides, and to allow the participants to speak before they did themselves, and;
  - experts were chosen to demonstrate a range of perspectives on genome editing, not all of them worked for CEITEC.
- 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 CEITEC 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 participants 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

Key challenges discussed by participants were mutually interlinked areas that influenced one another, these challenges can be grouped into different themes.

The biggest problems threatening mankind were seen as disease and insufficient food for a growing population. In terms of disease, participants discussed growing incidence of cancer and other diseases, epidemics, mental health issues, ineffective antibiotics with no alternative for them and overuse of medications.

Population growth causing overcrowding was mentioned, as well as economic problems. For example, economic interests of some people which do not take the future interests of mankind into consideration; the rich becoming richer and the poor becoming poorer; the waste of resources and raw materials, including food. The possibility of a fourth industrial revolution and the problem of an increasingly dispensable labour force were also discussed. Alongside this, other societal problems were mentioned such as addiction to technologies, a lack of control of the internet and increasing stress which leads to various illnesses.

Environmental problems were also a key theme. In terms of the environment the conversation focussed around global warming and climate change, specifically drought; shortage of water; degradation of ecosystems; extinction of species; growing waste; as well as overuse of plastic and microplastic in waters. Participants also mentioned despoiling of raw materials; devastation of seas; deforestation and poor food due to famine with natural ingredients being replaced by chemical ones.

"Foods used to be quality, not any more. The meat industry used to process quality materials. Many people buy cheap foods and then get allergies. Substitutes are made, E numbers."
Event 1, Prague

Finally, participants spoke about problems caused by globalisation. In relation to this, participants discussed the problem of the interest of global corporations, and power of non-democratic states, with China being given as a specific example. Migration as a result of the poverty of the "south", ideological pressure in the east and terrorism and "Islam" being blamed for this were also mentioned in the discussions. Other concerns were: war and conflict being used as a method to solve lack of resources; the interests of military industry; and the threat of the use of nuclear weapons.

2.2 Spontaneous views of solutions

Participants believed that science would be the solution to these problems. For example, some thought that food shortages could be solved through new crops, and genetic modification was mentioned as a potential way of doing this.

"Produce should be invented that is suitable for agricultural zones where agriculture is not productive. Migration generates from this poverty, there is hunger in those countries."
Event 1, Prague

"At present, modified foods are good to go in the USA. They have higher yields of corn. The question is whether change of genes in foods may cause something."
Event 1, Prague

Participants also discussed education, joint scientific disciplines, research with practice and the global sharing of information as potential solutions.

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

"There is always a question how long the art of medicine will work. Development of virus is accelerated. Treatment develops fast thanks to science, getting ahead. And all of sudden some disease from the other end of the world turns up and no one knows what to do about it."
Event 1, Prague

3 Views of basic research and genome editing techniques

Prior to the public dialogue event in Prague, Ipsos MORI conducted a workshop with CEITEC's stakeholders with expertise in genome editing from various backgrounds (bringing scientific, policy, legal, 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 CEITEC 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 CEITEC's research involving genome editing technology.

3.1 Participants' starting points

Participants overall had a vague understanding of key biological concepts such as DNA, genes, and cells, but all except one were unaware of genome editing. Participants were mostly aware that DNA contains information – instructions for the creation and functioning of a body, and that genes are present in DNA. They were aware that a cell is a basic unit of living organisms. Despite not knowing the exact definitions and having rather a faint idea of DNA, genes, and cells, and lacking detailed knowledge, participants could understand the scientific research, technologies presented to them and their implications.

Participants were initially neutral on the issue of genetic modification that is not in the interest of humanity, without contemplating the rightfulness, usefulness, or eventual consequences of the technology.

The participants welcomed information on scientific findings. However, they were not concerned with details on how scientific institutions operate, what they specialise in or how they are funded. A common viewpoint was that research always leads to progress and that discovering "dead ends that do not lead to the desired destinations" is a part of the research process. They strongly supported basic research and called for as much funding as possible for both basic and applied research.

None of the participants (bar one) were aware of genome editing technology. Participants tended to accept information on gene editing techniques with great expectations that this technology may assist mankind to overcome various challenges and solve problems that currently have not been solved. For example, they discussed the possibility of using the technology to cure life-threatening diseases and improve food supplies.

Participants imagined big potential for progress in agriculture and the food industry, appreciating that the techniques are cheap so will become affordable for more scientists to use, which enhances the potential of it: "more brains know more."

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

"Perhaps fewer babies with disabilities will be born."
Event 1, Prague

"Scientists should work more on fighting cancer. Environmental problems."
Event 1, Prague

"Species on the verge of extinction might be saved. They would be less sensitive."
Event 1, Prague

On the other hand, there was a concern about what might happen if such cheap and easily accessible genome editing technique like CRISPR Cas/9 was used in the interest of small groups: by those of a certain ideology, for religious interest, as well as interests of non-democratic countries (China was given as an example). Participants were concerned about the potential abuse of the technology for certain interests of those in power.

"The risk is that it can be abused by anyone and perhaps create some disease."
Event 1, Prague

"It might be abused, that only girls would be born, or boys only."
Event 1, Prague

Some questioned where the line should be drawn – where should genome editing techniques not be used? On the one hand, participants were optimistic about the technology being used to cure diseases, but on the other hand some cautioned the use of technology on humans due to concerns around a resurgence of eugenics. There were also singular objections made towards applying the technology to animals.

"I'd keep people out of it. I'd focus on plants, animals, it will be excellent in foods. Hitler started to play with people – the Germanic race."
Event 1, Prague

Participants also began considering the possible impacts of using genome editing technology on society. For instance, the possibility of creating an elite society with unlimited options, but alongside this, groups that will not be able to reap the advantage of the technology for curing severe diseases because they will not be able to afford it. This raised concerns about increased inequality due to the technology.

"So that we won't get to the stage where there is elite who will manufacture sports people, geniuses thanks to the fact that parents had money…"
Event 1, Prague

Overall, despite some concerns, participants seemed highly accepting of genome editing technology.

3.2 Views of basic research using genome editing technology

It was outlined that CEITEC conducts early-stage, basic research aimed at understanding biological processes, which may or may not lead to immediate practical applications. Participants did not distinguish between basic and applied research. When this difference was pointed out to participants, they assumed that basic and applied scientific research were closely linked. Participants saw trial and error as part of the natural research process. Therefore, participants showed strong support for basic research, even where it may not lead to applied outcomes. Czech people deeply respect scientists and their knowledge, because they consider their work some of the most useful to mankind. According to public opinion, science should receive generous investments from the state.

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

Case study 1: Re-programming immune system cells – this case study outlined research that scientists at CEITEC are doing to try and develop a new treatment for cancers such as leukaemias and lymphomas, called CAR-T therapy. This involves editing cells using CRISPR to recognise the specific combination of changes in that patient's cancer.

Case study 2: Understanding how plant molecules work – this case study explained the work that was being done to study how CRISPR and molecules similar to Cas9 are involved in plant's immune systems, in order to understand how these molecules work.

Case study 3: Understanding how viruses work – this case study describes how bacteria and viruses work and how CEITEC scientists are studying how bacteria-infecting viruses work, and how they invade bacteria cells.

3.2.1 Case study 1: Re-programming immune system cells

Hope concerning the existence of successful treatment of cancer impressed the participants. The potential contribution of this use of the technology was so great that no one thought of a single argument of potential misuse of the technology. The fact that the potential of technology so far is to treat only two cancer types had no impact on the support given to this research by the participants.

Participants were keen for this type of research to continue even if the treatment cost was very expensive and is currently only able to treat a few individuals. Participants had absolute trust in scientists' abilities to apply findings from this research in other types of cancer in the future, which would eventually increase the number of recipients of treatment with the use of genome editing. They had faith that genome editing treatments would become cheaper over time.

"If it is for individuals initially then is will massively spread so it will be simpler."
Event 1, Prague

"I disagree with the opinion that is it not fair if initially one rich person only will have the treatment and others will be dying. Unless they start dealing with it, it will never be for masses."
Event 1, Prague

"It will not be fine-tuned in the beginning. A sportsman, a singer will have it and only then the others…But it is positive."
Event 1, Prague

The use of animals in research was a controversial issue for many people, however there was generally agreement that research carried out on mice is acceptable. Tests done on pigs, dogs and monkeys were generally seen as unacceptable.

"I mind that they induce cancer in those mice."
Event 1, Prague

"Who are we to judge which animal is inferior and superior?"
Event 1, Prague

"If someone suffers from incurable form of cancer but has a chance that it will work then [animal] testing is appropriate."
Event 1, Prague

Even though participants were concerned about animal welfare and disapproved of research in which animals were harmed, participants tended to judge overall that this testing was worth this harm, in order to help find cures for mankind.

3.2.2 Case study 2: Understanding how viruses work

Participants found the text of the case study comprehensible, as it was written in non-scientific language. People could appreciate that the research may help to solve the problem of bacteria becoming resistant to antibiotics. This could lead to an effective alternative being invented instead of using antibiotics, the use of which can have the adverse effect of killing beneficial bacteria, and not just harmful bacteria.

"If it kills five viruses it is better than the antibiotic that kills everything."
Event 1, Prague

The mention of learning how to programme viruses in the case study generated a question among participants about how it will be possible to control the use of research results. People thought that it would then be possible to programme viruses to accomplish any task, and therefore that technology might then be easily abused and used against people.

"It's super that we can point at bacteria we want to damage. But there is also the danger of misuse!"
Event 1, Prague

"It is a noble idea but a bit naive."
Event 1, Prague

The perceived potential for this research in helping mankind to combat diseases was welcomed by participants so much that they could ignore the potential risk of its abuse. Overall participants definitely supported the use of genome editing techniques in this research.

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

"Development would have to halt in order to disable misuse. I'd carry on, it's positive!"
Event 1, Prague

Participants agree on the necessity of strict government checks and regulations to guarantee that results will only be used for the purpose of 'good' and to ensure that the technology was not misused.

3.2.3 Case study 3: Understanding how plant molecules work

Participants struggled to understand this case study as they found it quite academic. However, they welcomed the idea that this research could lead to more resilient, and thus more lucrative crops.

"That the plants use it to defend themselves against infections. They will be stronger, better and it will be more beneficial for us."
Event 1, Prague

The participants considered this type of research helpful, because scientists could find out how plants defend themselves against infections. They believed that such an intervention to a plant ecosystem could then be transferrable to humans.

Participants were not able to distinguish this as an example of basic research, but they did not question its goal or purpose. Instead they considered it important, and usable in the future. This optimism is based on cases of 'random' discoveries, which lead to a series of further studies concerning other topics. Without research, which does not always necessarily bring results, there would not be new discoveries. As non-scientists, participants did not feel competent enough to judge the usability/applicability of the basic research.

"If I do not research anything, I cannot find anything out."
Event 1, Prague

"That's how penicillin was discovered, he left for a week and then it was there, only later on they found out what it was. And Madame Curie as well discovered the X-rays, and then she put her hand in there. Research is here to find out things, but you always have some errors."
Event 1, Prague

"I am fascinated by the revelation that it is real. We take it as granted, the discovery, that it is not a sci-fi, that it is real. That´s fascinating!"
Event 1, Prague

3.3 Views of different groups and how they differ

- Men found the technology particularly appealing because it is low cost and therefore accessible, and also because of how broad the potential uses of the technology are.

"It's terribly fast technology. It will help very soon."
Event 1, Prague

- Those from a higher educational background were better able to understand the risks of using these genome editing techniques.

- Women focused more so on the vision of healthy people, elimination of dangerous diseases, and possibilities to only have healthy children.

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

3.4 Implications for CEITEC

Despite initially having a very low level of awareness of genome editing techniques at the outset, participants were very enthusiastic about the potential for this technology and the impact it could have on their lives. Therefore, it will be important for CEITEC to manage expectations around what they are likely to achieve from their research in the near future when communicating with the public. Participants greatly valued and accepted the basic research CEITEC conducts using genome editing techniques, even if this might not lead to applied solutions and saw 'dead-ends' as part of the research process.

There was some concern around making sure the technology was used responsibly so communicating what regulations and protections there are around the technology will also be important.

4 Views of possible future uses of genome editing

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

- Genome editing for **medical purposes** – genome editing techniques might be able to help tackle diseases, through the use of non-heritable genome editing as well as heritable genome editing. Experts involved in the discussions also introduced the idea of new treatments such as gene therapies, which are taking place in clinical trials[11], 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 Czech Republic. 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.[12]
- Genome editing for **human traits** – the idea that in the far-off future, genome editing could enhance human traits such as intelligence or endurance, as well as cosmetic traits such as hair or eye colour.
- Genome editing **for animals and livestock** – genome editing could make animals more resistant to disease, and enable more sustainable farming practices.
    - As part of this case study we also spoke about the possibilities of editing the genomes of **insects** such as mosquitoes to inhibit their ability to develop and spread malaria, thus potentially bringing about medical benefits.

[11] https://www.discovermagazine.com/health/gene-therapies-make-it-to-clinical-trials

[12] 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 Czech to use in the events. These case studies equipped participants with information that allowed them to weigh up the possible benefits, as well as implications, arising from developing treatments and therapies using genome editing techniques such as CRISPR/Cas9. The handouts shown to participants can be found in Appendix D. These handouts were designed to enable participants to reach some conclusions on acceptable uses and what trade-offs, and under what circumstances, they are willing to make these. 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 CEITEC uses genome editing to better understand fundamental biology, CEITEC wanted to know if it should be helping to inform the public about how other researchers and scientists might deploy genome editing technology. For example, others could build on the learning CEITEC 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 CEITEC.

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')

Participants on the whole agreed with the idea that somatic genome editing for medical purposes could improve life of individuals with severe disease or a disability.

Participants were surprised by the idea that the technology might not be accessible to all affected and be applied all diseases. They believed that society should bear responsibility for the costs of all people having equal healthcare rights and that accountability for such decisions ought to be from a committee of experts in healthcare and science.

"I don't know which disability is worse for an individual."
Event 2, Prague

The idea that there could be inequality of access to the technology, with only the wealthiest being able to access it hampered the enthusiasm of some participants who until then were arguing for as fast an introduction of the technology in practice as possible. Social inequality in this case was viewed as bringing

insurmountable social handicaps for the poor.[13] Some participants felt this technology could create a new form of inequality in Czech society and therefore could be a step backwards in terms of progress.

"This information significantly shifts my opinion on the technology. A class of sorted out disabled people would be created here. What we have achieved after the revolution [Note: end of the communist government in 1989] with people with disabilities would return, they would be totally excluded."
Event 2, Prague

Not all those in the discussions were as concerned about the potential for inequalities around the use of the technology. In their opinion, there have always been disadvantaged groups of people in society (e.g. those disadvantaged by their health condition), and this will naturally continue in the future. Others, out of helplessness regarding how to come to terms with the likely unfair access of many people to genome editing technology, accepted that the technology could initially advantage only certain groups in society.

Some participants were worried that the widely accessible and cheap nature of the technology may, in some countries, lead to manipulating people's genes for negative uses.

"No questions asked in China. And it's not China only but also the Americans, the Russians."
Event 2, Prague

4.1.2 Views of genome editing plants and crops

The examples of genome editing of plants presented to participants did not appeal to participants, as they were not considered to solve important issues. They felt aesthetic adjustments of crops were unimportant. Participants were also not convinced that it is necessary to modify wheat that would be gluten-free as people with severe allergies to gluten can alternatively solve this problem with their diet.

Instead of creating new, modified crops, participants would rather see a return to original crops. In the opinion of participants, the taste as well as aroma of produce sold at present in the Czech Republic cannot be compared to what used to be sold many years ago.

"Here, there used to be fruit and vegetable with taste and long life. These days, it is lacking taste and smell. I remember the times when we used to queue for bananas, they smelled so nice. Same with strawberries."
Event 2, Prague

[13] After 1989, a big change was made in the position of people with physical disabilities in the Czech Republic. Children with disabilities started to be integrated into mainstream school classes only since then. Concern about disabled people started to be projected in building regulations only after 1989, making disability access to pavements, into buildings and flats mandatory. While the attitude of the Czech society to people with physical disabilities has already changed, there remains prejudice in relation to mental health issues.

"I don't think so. There are certain substitutes that can replace it. There are so many food allergies that we would have to modify everything. No way!"
Event 2, Prague

There was some concern that plants modified like this would push the original (non-genetic edited) plants out of the natural ecosystem.

Despite these initial concerns, participants did see value in using genome editing techniques on crops in order to make them more resilient to the environment. They accepted the genome editing of plants in order to adapt them to be able to survive in increasingly common droughts.

4.1.3 Views of genome editing animals and livestock

Participants had difficulty understanding the future possibilities presented for the use of genome editing technology on animals. They were not concerned about the potential for worse handling and welfare of animals because, unlike in the past, in the Czech Republic (as well as in the EU more widely), there are clear regulations to handle animals well and to maintain their good quality of life.

Participants believed that poultry is currently preventatively treated with doses of antibiotics that then make their way into the bodies of those who consume them. Therefore, they did not favour further manipulation of animals.

Economic arguments of using genome editing technology to save on costs of breeding animals could not outbalance participants' concerns over its use.

"One day someone will do it also to us. We will be prettier and stronger..."
Event 2, Prague

Regarding editing the genomes of insects, participants were concerned about this interfering with ecosystems and disturbing the food chain.

On the contrary, the transplantation of animal organs to humans was accepted by participants because it was seen as having beneficial, life-saving potential for humans.

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

Almost all participants rejected the use of germline genome editing in humans due to little knowledge of the biological response to this intervention. There was strong concern about unknown, unintended consequences and the possibility of off-target effects.

The vision of hereditary germline genome editing created a reaction among participants ranging from strong uncertainty to displeasure. Participants understood that it could be many decades before the consequences of germline genome editing are fully understood. The biggest concern was about unintended and irreversible changes to the human genome that would cause the birth of a person with some genetic damage or

disadvantage. Additionally, participants felt that such a change may only become apparent in future generations further down the line.

"I'd be concerned about hereditary diseases. Yes, in case of severe diseases. But the time for verification is horribly long, we don't know what will be born in 30 years."
Event 2, Prague

"I'd be concerned to change something for good. It may happen that a person will develop some other disability."
Event 2, Prague

"Some countries may release it and they say what child they don't want, with that disability. Then when they find out that the child has some damage they won't want it."
Event 2, Prague

However, participants did not reject the use of germline genome editing in the future, as they though it may assist mankind to tackle diseases that devastate the lives of the ill and of people close to them. For this purpose, germline genome editing was viewed as being justified, but only on the condition that scientists will have conducted enough research to fully know the consequences of it on the human body.

Women in particular were impressed with the future possibility to cure severe diseases or prevent the birth of a child with congenital damage. For this, they were willing to risk the uncertainty of possible adverse health effects of genome editing. They viewed the certainty of eliminating disease / disability as outweighing the possible negative consequences.

"Every mother wishes for the baby to be fit and well above all. If she has a chance to influence it, she will be very happy. When there are hereditary predispositions, she will go for it. If she is a mother who wants the best for her baby, she will go for it despite the risk that she is being tested. She will try it rather than have a baby with damage. That's what I'd do."
Event 2, Prague

For safety reasons, at present participants would opt for somatic gene modifications over germline genome editing, in order to heal people suffering from severe diseases or to remove severe physical or mental defects / disorders.

"We are in the beginning, we don't know now what it will do in 30 years, I'd rather be more careful. For the time being, it should be removed in children only."
Event 2, Prague

4.1.5 Views on heritable genome editing for non-medical purposes

The overwhelming majority saw the use of genome editing to adjust humans' features as unnecessary and unnatural. People anticipated that the practice of improving people according to their desires would result in the degeneration of mankind.

"I don't like it at all, it is like creating robots. We are going against nature. I am looking forward to what colour the baby's eyes, hair will be. I don't want to intervene."
Event 2, Prague

"I am strongly against it too. Then we would have only Barbies and Kens flying around. Nobody will be beautiful. This is the line we would not want to trespass."
Event 2, Prague

"I disagree with changing the hair colour. Mankind will extinct themselves by making themselves more and more perfect. Then there will be new beginning, from a micro cell to their extinction. It is progress but then it will be so perfect that there will be no room for continuation."
Event 2, Prague

There was a view that being able to make babies "to order" might result in fewer people living as couples and fewer women bearing children.

"Then for example people might stop looking for partners, as they would have no reason."
Event 2, Prague

The idea of slowing the ageing process using genome editing technology was approached by the participants with caution. The promise of using the technology to live to an old age appealed to only a few participants. Participants instead spoke of growing current age-related problems as a part of extended old age, meaning that people are reaching a high age, but a growing number have age-related dementia. Therefore, participants thought that it is not necessarily desirable to live longer. This model also faced criticism because a growing population of the elderly would then struggle to provide for themselves.

The idea of genome editing being used for any modification requested by people reduced participant's enthusiasm for fast application of the technology in practice. They worried that the technology might be used for less than "noble" purposes and the commercial use of it may not have reasonable controls. Participants realised that even when the technology is controlled by the government there will always be a country or an individual who will use it in contradiction with the agreed rules (as has already happened in China), to profit financially or in the interest of power.

"There will be scientists who will want to become famous through this, and to profit from it."
Event 2, Prague

Regarding future possibilities of modification of the human genome, one participant even suggested the creation of a bank of natural human genomes that could be used as a resource.

"Talking of foreseeable future, just like plants are stored in an archive, genuine genes ought to be stored too."
Event 2, Prague

4.2 Implications for CEITEC

Scientific institutions ought to inform the public of their work and publish the successes of their research as much as possible. In the opinion of the participants, a scientific institution cannot be held accountable for how the findings from the work they contributed to are used in the future by others. This is because there was a prevailing view that scientific institutions have a duty to ensure their work is as open and widely available as possible, including for use by others.

"A research institute should create conditions for scientists to carry out their research. It should lead and show new ways, new options. Let someone else let decide on the consequences. I'd leave it to public atmosphere and politicians."

Event 2, Prague

5 Communication and engagement

A key objective of this public dialogue for CEITEC 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 CEITEC 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'[14] created for the purpose of these public dialogue, in collaboration with artist Emilia Tikka and another ORION partner organisation (MDC, Germany), and were asked to reflect on it.

5.1 Communications context

As an ORION partner, CEITEC is already committed to being accessible, open and transparent with members of the public. CEITEC regularly publishes public-facing articles on their website and social media pages about research being conducted.[15]

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

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

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

Participants were initially unsure of the best way that the ORION partners should communicate about their work to the public. But, they advised the institutions to communicate about their successes. For example, they felt it would be effective to show examples of diseases that might be treated with genome editing, and ideally to supplement this with stories of actual people as these would be more relatable. Participants considered it important to show where the use of genome editing could bring benefits as opposed to examples where genome editing is not used (e.g. treatment of cancer with genome editing versus treatment with chemotherapy).

Participants advised not to go into too much detail about how the technology works because they thought many people would not understand it and would therefore lose interest. To raise discussion about the technology with the public, they thought it was best to show what potential benefits the technology could bring. This could include showing how genome editing might help to improve foods such as making crops more resistant to droughts.

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

[15] https://www.ceitec.eu/news

"To show what benefit it brings in the countries where it is permitted."
Event 2, Prague

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

The participants felt it was important to disseminate information about genome editing to the widest possible audience. Therefore, they emphasised television, which is traditionally considered to be the medium with broadest reach. Younger participants also suggested social media as a communication method. The following ideas were suggested as ways of communicating about the technology to the public, many of which relate to video/televised approaches:

- Showing documentaries or animations about genome editing in the waiting rooms of healthcare providers, to include them on the playlists of trains and coaches where passengers watch movies during the journey
- Including issues related to genome editing into TV quiz programmes
- Including the theme of genetics on popular educational TV programmes (e.g. Zázraky přírody/Wonders of Nature, Focus Václava Moravce, Hide Park Daniela Stacha)
- Including it as product placement into TV series relating to healthcare (e.g. Ordinace v Růžové zahradě/Rose Garden Surgery)
- Approaching the Czechs who are fond of gardening about genome-edited plants through DIY TV programmes (e.g. Receptář dobrých nápadů, Hobby mé doby, Po lopatě)
- Information about genome editing could be presented via games and building sets: "Young genetic", a similar board game to Monopoly, Lego
- Publicity throughout cities (e.g. public transport stops)

The following were considered the best methods of communicating about genome editing with people as they were popular:

- For the middle aged and older: TV
- For younger age groups: social media

"I watch the academy of science on the Instagram and learnt a lot there."
Event 2, Prague

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

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 CEITEC website
- Social media
- Citizen science
- Citizen's forums
- Printed media
- Public Science fairs
- Exhibitions showing the technology and Open Days
- Theatrical performances

Out of the various engagement methods presented as options to participants, the following were considered to be the most effective formats for educating people on the subject:

- Animated videos (e.g. 'Byl jednou jeden život'/'Once upon a time')
- Documentaries on documentary TV channels (e.g. Zoom, Discovery, Spectrum, National Geographic)
- Public events about science (e.g. 'Dny vědy'/'Days of science', věda v ulicích/Science In the Streets, and scientists visiting schools)

Other methods of communicating were considered to have a limited appeal and may reach only those with a deep interest in science. A summary of views on these methods is below:

Academic journals: Participants did not read academic journals, however they would read an article about science or an interview with a scientist printed in a lifestyle or news magazine (for example: Spektrum, National Geographic, Epocha, Lidé a země, Reflex, Respekt, Týden, Reportér, Interview).

CEITEC website: Only two of the participants had ever visited the website. It was deemed unlikely that most people would seek this out.

Citizen science and citizen's forums: Participants did not know about these activities (aside from the current public dialogue) and had no experience of these. Participants enjoyed the public dialogue events and considered such events effective for transmitting information about the technology. On the other hand, they felt these were ineffective at reaching the public more widely.

Public Science Festivals: Events in public such as 'Science In the Streets' were considered to have potential to attract people but involve an element of chance as members of the public would have to walk past them, likely by accident.

Exhibitions showing the technology and Open Days: These types of events were considered to attract only a minor segment of population who have a pre-existing interest in science.

Theatrical performances: Participants said they would not commonly go to the theatre, and if they did, they would be unlikely to choose to see a performance about a scientific topic.

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

Method	Pros	Cons
Animated videos	Could be credible way of educating the public in scientific issues thanks to very popular animated series 'Once Upon a Time... Life'	Could be seen as more child-focused
Videos of scientists talking about their work	When being in personal contact with scientists, people are fascinated with their knowledge and want to learn more	It would work only in cases where the presented scientist was a well-known, famous person as otherwise people would not pay attention to such a video
Television	Good way to reach those who are middle aged and older	
Academic journals		Limited appeal and may reach only those with a deep interest in science
The CEITEC website		Limited appeal and may reach only those with a deep interest in science

Social media	Popular with young people – a good method for reaching this age group	
Citizen science		Limited appeal and may reach only those with a deep interest in science Participants had not heard of this
Citizen's forums (such as dialogues, juries, and assemblies)	Effective for transmitting information about the technology	Limited reach
Printed media		Sale of printed media have declined and people tend to read the news on the internet.
Public Science festivals	Potential to attract people if they came across this	Limited appeal and may reach only those with a deep interest in science
Exhibitions showing the technology and Open Days	Extremely effective for people for people enthusiastic about science, who visit such events	Limited appeal and may reach only those with a deep interest in science
Theatrical performances		Limited appeal and may reach only those with a deep interest in science

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

The ORION consortium wanted to incorporate a piece of art to this public dialogue as a different means of encouraging participants to discuss about a potential future scenario arising from genome editing technology. Accordingly, the ORION project launched a competition for commissioning this art piece in May 2018, which was managed by MDC, the ORION partner in Germany. Emilia Tikka, an artist, designer and PhD candidate at Aalto University, The School of Arts, Design and Architecture in Helsinki, won the bid with her work entitled '*Trajectories of longevity and CRISPR*' (*AEON*). Images of the art piece can be found on Emilia Tikka's website.[16] For this art piece, Emilia designed a speculative scenario of a rejuvenation technology embodied as a device for daily use and narrated as a fictional photographic story.

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

Figure 5.1: Images of AEON Trajectories of longevity and CRISPR

An aim of the art piece was to provoke discussion around the issues arising from one potential future use of genome editing technology. It was successful at provoking debate in the public dialogue events; discussion raised by the art-piece was heated and it was apparent that the art-piece was able to convey lots of information about the potential consequences of the use of genome editing technology.

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

"It's a nonsense to be around for 300 years, a human being is not adjusted to that."
Event 2, Prague

The art piece allowed participants, who in majority rejected the idea of life extension, to think through specific consequences of the decision "not to grow old". They realised that the mental stage of a person is not supported by genes but experiences that accumulate, despite the decelerated ageing of a body and the brain processing them, shaping life values and attitudes. They realised it could be a problem if there were individuals who exercised "irreversibly" postponed aging in an environment where others age at a normal rate.

"One would be left alone, their real peers would be dead, they would not click with the young due to life experiences and attitudes. So what would it be good for?"
Event 2, Prague

"I wouldn't want to be with a 70-year old brains among 20-year olds. I'd see them as idiots."
Event 2, Prague

"A dad will be younger than his child."
Event 2, Prague

Discussion on the artwork also focussed on the age imbalance of the couple depicted (an elderly woman with a young man).

"If it was the other way round it would not be odd. We would not even think about it."
Event 2, Prague

"He's got many options that she does not. She is waiting for the end."
Event 2, Prague

However, the success of the artwork was conditioned by viewers getting additional information – the work was introduced in the video shown of it by the author who indicated the theme of the work ahead of participants viewing it. The participants needed clarification on the relationship between the main protagonists of the artwork. Without this explanation, some felt that the artwork could be interpreted as a story of a mother and her son, showing an ordinary life of these people.

The artwork succeeded in raising questions about the effect of genome editing technology on human life.

However, participants thought it might only appeal to a small portion of society, namely those interested in art.

6 Conclusions & Recommendations

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

Table 6.1: Table of conclusions & recommendations

	Conclusions	Recommendations	Recommendation for:
1	Participants anticipated that awareness of genome editing among the public will gradually grow. Initially, scientists will learn from the examples of unintended effects. They are willing for scientists to take this risk, believing that the technology will push the boundaries of progress forward (especially in medicine). In their opinion, the risks of using the technology are widespread but progress is not possible without taking these risks.	Inform the public about the technology and its potential contributions to society, as well as on the current uses of the technology in the world, especially on the achievements and successes of the technology so far. It is important to avoid providing the public with technological aspects in detail, as most people would be discouraged by this. It should also be made clear to the public that the application of the technology will be subject to high levels of regulation and checks by governmental as well as multi-national agencies.	• Scientists should help inform the public about the technology • Communication and Engagement specialists should also help with providing the public with clear information
2	Participants often could not differentiate between basic and applied research. In their opinion, every scientist and their work in either of these two types of research is deeply respected because both forms of research were viewed as resulting in progress. There was strong support of funding for both basic and applied research	Emphasise to the public the high standard of Czech scientists who, if their research is funded sufficiently, could achieve highly, like scientists in other countries. When communicating with the government and negotiating funding for research, it will be important to be aware of great expectations of society from science – there is strong trust in scientists and scientific institutions can count on great support from	• Scientists will have an important role in communications with the public. Because of the trust in them, it will be important for them to communicate clearly with the public • Communication and Engagement specialists can support scientists in

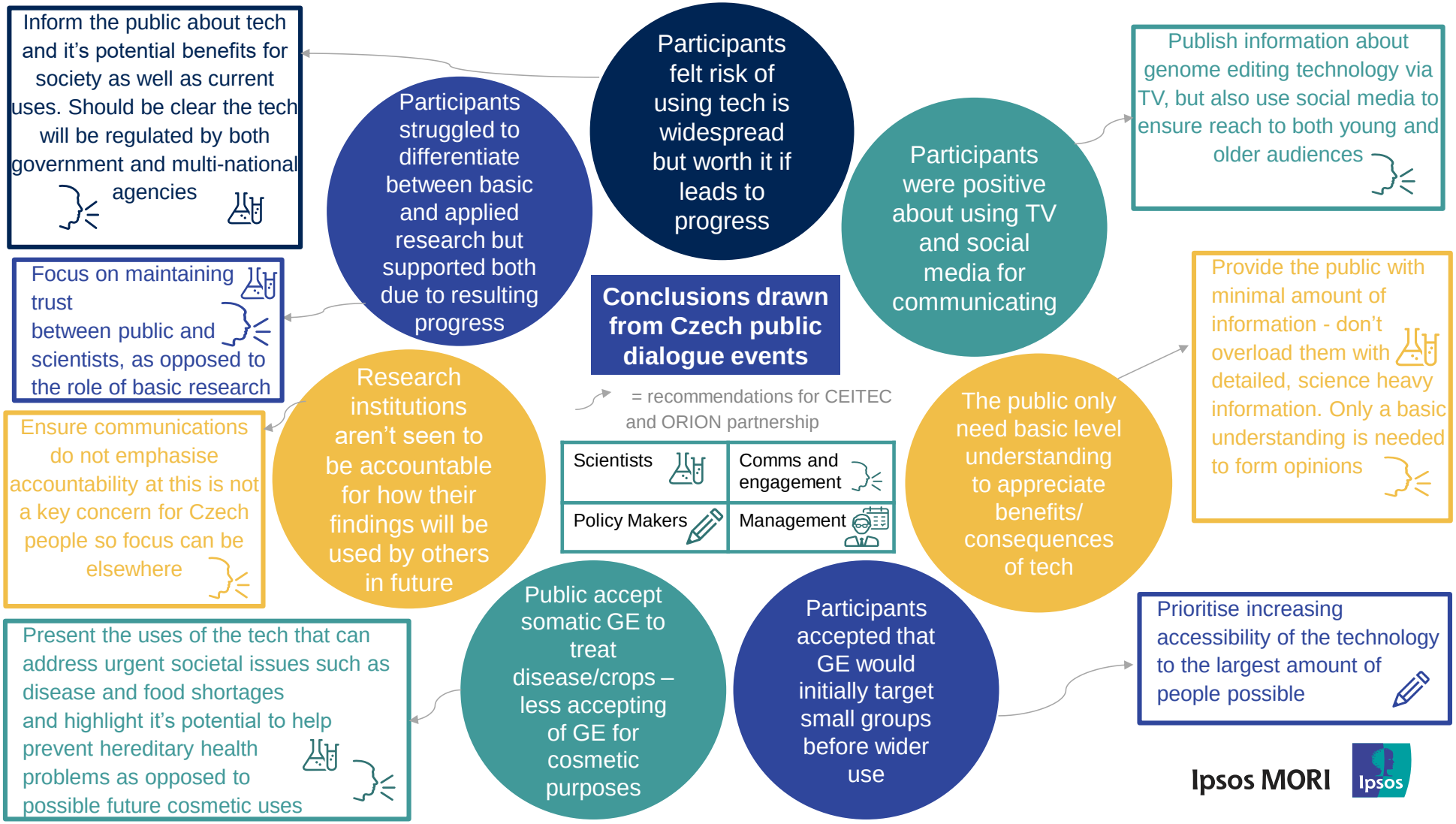
	and this was considered to be a fundamental task of the state.	ordinary people, but the public have high expectations of this science being used to cure diseases. When having these discussions, it will be important not to point at the role of basic research, as this type of research does not play a role in the public's decisions to support science: they do not relate to this term.	the best ways to do this
3	In participants' opinion, research institutions conducting the basic research are not accountable for how their findings will be applied by other institutions in the future. They believed the main task of any researcher is to ensure their findings are open for implementation by other scientific institutions. The institutions working in basic research then cannot be responsible for who uses their findings or how they are used.	Ensure that communications do not focus on how the ORION open science partnership's basic research findings are applied by other institutions as this was not a concern for those who participated in the public dialogue events in the Czech Republic and therefore people might not understand what this discussion relates to.	• Communication and Engagement specialists should ensure that this is not a focus of the conversation around genome editing
4	What is at present fully acceptable for the public is the use of somatic genome editing techniques in humans for the purpose of treatment of severe diseases, physical and mental disabilities/disorders, and the genome editing of crops. What is considered less acceptable is modification of people's features for cosmetic	Present the use of the technology as a potential way of solving urgent problems faced by mankind (curing severe diseases, making crops more drought resilient). Alongside this, a willingness should be shown to develop applications of somatic genome editing in practice and to present genome editing as research of the future that could help to supress dangerous	• Communication and Engagement specialists should ensure that the conversation is framed this way • Scientists should consider ways to present their research so that it emphasises

	purposes, which is why participants did not anticipate that research institutions would get involved in this type of application. Regarding this, participants were concerned about the desires of some individuals to adjust their features and the features of their unborn children. They were concerned about what society would be like if people can easily amend their qualities and skills. They were also concerned that the technology might be abused by non-democratic states.	hereditary health problems (with a similar purpose to immunisation). Conversely, there should not be a focus on presenting work that could lead to the potential amendment of people's features.	the problems they are looking to address
5	Participants were tolerant of the idea that initially only small groups of people would benefit from the use of genome editing technology, as long as eventually there would be further spread of using the technology for treating more diseases and with more patients.	Prioritise increasing accessibility of the technology to the largest amount of people possible.	• **Policy makers** should consider how the technology can be made accessible to all
6	Before the public dialogue events, none of the participants were aware of the existence of genome editing, except for one. No participants struggled to comprehend the principle of genome editing and its possible consequences once they had participated in the events,	Publish information about genome technology via TV, but also use social media as a way of reaching both young and older audiences.	• **Communication and Engagement specialists** should consider television and social media as methods of reaching a wide audience

	including those who had only basic knowledge of biology. Participants wanted to be informed mainly about the possible benefits of the technology for people. They did not believe there was any point in providing detailed information to the public about how the technology works, as only those with a keen interest in science would want to engage with this information. Participants were very positive about the use of televised means as a method of communicating about the technology, including the use of animated videos. They also saw the benefit of online approaches like social media.		

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

Figure 6.2: Diagram of conclusions & recommendations



Appendix A: List of stakeholders who attended the stakeholder workshop

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

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

Stakeholder name	Organisation	Role
Kateřina Ornerová	CEITEC	Strategy and Science Department
Ester Jarour	CEITEC	Spokesperson, PR and Comm. Manager
Pavla Foltynová	CEITEC	Head of Strategy and Science Department
Petr Jaroslav	Institute of Animal Science Biology of Reproduction	Scientist
Aleš Pečinka	Institute of Experimental Botany, Centre of the Region Haná for Biotechnological and Agricultural Research (CRH)	Scientist
Radek Šindelka	Institute of Biotechnology of the Czech Academy of Sciences Laboratory of Reproductive Biology	Scientist
Petr Chlapek	Masaryk University	Scientist
Zdeněk Opatrný	Charles University	Professor Emeritus
Zuzana Doubková	Department of Environmental Risks and Ecological Damage, Ministry of the Environment	Head of Unit of Genetically Modified Organisms
Tomáš Boráň	State Institute for Drug Control (SÚKL)	Section Director

Jana Fischer	U.S. Embassy Prague, Foreign Agricultural Service, United States Department of Agriculture	Agricultural Specialist

Appendix B: List of experts who attended the events

The table below shows a list of experts at the public dialogue events, who agreed for their names and roles to be listed in this report.

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

Stakeholder name	Organisation	Role
Event 1		
Zdeněk Opatrný	Charles University	Professor Emeritus
Aleš Pečinka	Institute of Experimental Botany, Centre of the Region Haná for Biotechnological and Agricultural Research (CRH)	Scientist
Tomáš Moravec	Institute of Experimental Botany	Head of Laboratory of Virology
Event 2		
Zdeněk Opatrný	Charles University	Professor Emeritus
Tomáš Moravec	Institute of Experimental Botany	Head of Laboratory of Virology

Appendix C: Case studies shown to participants

Re-programming immune system cells

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

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

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

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

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

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

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Understanding how plant molecules work

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

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

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

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

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

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Understanding how viruses work

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

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

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

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

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

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

Appendix D: Future possibilities of genome editing handouts

Future possibility 1: Genome editing for medical purposes

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

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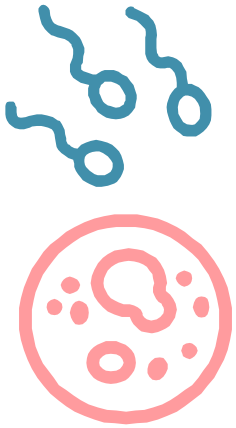
Future possibility 1: Genome editing human embryos

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



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Future possibility 2: Changing traits in humans

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

- Some predict it may even be possible to **slow down ageing**

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Future possibility 3: Genome editing animals

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

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

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

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Future possibility 4: Genome editing plants & crops

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

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Appendix E: Information shown about the art piece

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

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

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

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

Appendix F: Glossary of Terms

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

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

Appendix G: Advisory Group & Review Group members

International Advisory Group members

Name	Organisation	Role
Simon Burrall	Involve Foundation (UK)	Senior Associate
Marta Agostinho	EU-LIFE	Coordinator
Luca Franchini	Fondazione ANT (Assistenza Nazionale Tumori) Italia Onlus (Italy)	Psychologist (MSc. Social, Work and Communication Psychology)
Annette Leßmöllman	Faculty of Humanities and Social Science, Karlsruhe Institute of Technology, (Germany)	Vice-Dean
Michael Wakelam[17]	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)

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

Czech Review Group members

Name	Organisation	Role
Kateřina Ornerová	CEITEC	Head of Strategy and Science Department
Ester Jarour	CEITEC	PR and Communications Manager
Pavla Foltynová	CEITEC	Research and Development Manager
Karel Říha	CEITEC	Director for Research
Nikola Kostlánová	CEITEC	Scientific Secretary

Appendix H: Babraham Institute & Ipsos Project Team

The Babraham Institute Public Engagement Team

Name	Organisation	Role
Emma Martinez-Sanchez	The Babraham Institute	Public Engagement ORION Open Science Project Officer
Stephanie Norwood[18]	The Babraham Institute	Public Engagement ORION Open Science Project Officer (maternity cover)
Tacita Croucher	The Babraham Institute	Public Engagement Manager
Hayley McCulloch[18]	The Babraham Institute	Public Engagement and Knowledge Exchange Manager

Ipsos project team

Name	Organisation	Role
Michelle Mackie	Ipsos MORI	Research Director and Head of Ipsos Dialogue
Graham Bukowski[18]	Ipsos MORI	Associate Director
Sarah Castell	Ipsos MORI	Head of Futures
David Hills	Ipsos MORI	Senior Research Executive
Holly Kitson	Ipsos MORI	Senior Research Executive
Amber Parish	Ipsos MORI	Project Administrator

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

Jana Sojková	Ipsos Czech	Account Manager
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About Ipsos MORI's Social Research Institute

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