

# Potential uses for genetic technologies: dialogue and engagement research conducted on behalf of the Royal Society



**Findings Report**  
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**Report Authors:**

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# A study to inform the policy environment for the use of genetic technologies in plants and animals, and catalyse early debate around potential future uses of genetic technologies in humans

**This report has been prepared by Hopkins Van Mil: Creating Connections Ltd (HVM). It was commissioned by the Royal Society.**

Genetic technologies have a long and divisive history, with much higher levels of concern about the health risks they pose in the general public than in the scientific community, especially in the context of plants grown for food. Developments in the techniques for modifying genetic material mean a much wider range of applications are now in scope, including possible human and animal applications. As the UK is leaving the EU, it will have new choices about its regulatory framework for genetic technologies. This is why the **Royal Society** embarked on a genetic technologies policy programme for which gaining an understanding of public views on the benefits of and concerns about the uses of genetic technologies was an important starting point.

The Genetic Technologies Public Dialogue was designed and delivered by **Hopkins Van Mil (HVM)**. HVM specialises in social research programmes. It puts people at the centre of big issues and it does that by asking questions and listening. Emotionally engaging subjects such as genetic technologies affect a range of people, but their opinions can get lost or swamped. As expert facilitators Hopkins Van Mil create safe, neutral and productive spaces for the public, policy makers and policy shapers to share their views.

The study will feed into the evidence base which informs the Royal Society's engagement with policymakers, industry and the research community in the UK and internationally.

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# Executive summary

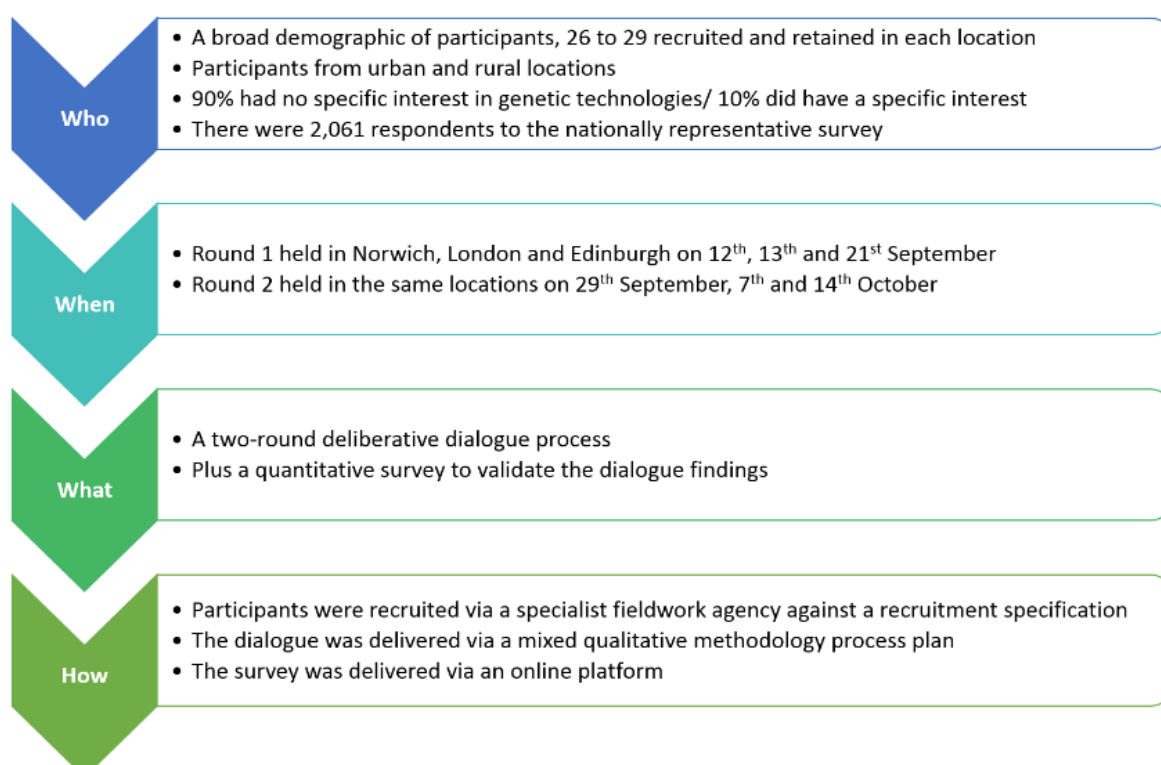
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## Background and methodology

In July 2017 the Royal Society commissioned Hopkins Van Mil (HVM) to run a public dialogue to explore the range of views that individuals hold concerning which potential applications for genetic technologies should be developed, why, and under what conditions. HVM designed and delivered a two stage process comprising a deliberative public dialogue, conducted from 12 September to 14 October, and run in:

- **Norwich:** on the application of genetic technologies to plants and micro-organisms including as sources of food, medical compounds or raw materials
- **London:** near to medium-term future (0-10 years from the present) scenarios for the application of genetic technologies to humans, including heritable and non-heritable interventions for both the treatment and prevention of disease and disability and the enhancement of traits and abilities
- **Edinburgh:** the application of genetic technologies to animals, including animals as pests, sources of food, companions and wild creatures.

Followed by a nationally representative survey of the UK population the fieldwork for which took place from 1 to 13 November 2017. The principle purposes of the research were to review the applications that a majority of respondents did or did not support, why and under what conditions. The research included an exploration of commonalities and differences in attitudes; views on who is trusted to work on and/or advise and inform on technologies or applications and why; all framed in the context of global challenges that society must address. The methodology employed is summarised as:



## Genetic technologies and global challenges

This chapter explores participants' views on global challenges, the relationship of genetic technologies to finding solutions to those challenges, and alternative solutions that participants highlighted as their discussions unfolded. This is combined with an analysis of people's hopes and fears around genetic technologies. Participants were prompted to discuss the global challenges faced by society in the first warm-up discussion of round 1. They raised a significant number of challenges which the report authors have grouped into the following broad themes:

- Addressing inequality
- Responding to social change
- Preventing and reversing environmental harm
- Keeping people healthy
- Keeping populations safe.

The hopes and fears for genetic technologies raised by participants having heard the initial contextual presentation on *A History of Genetic Technologies* are integrated into this chapter. The principle hopes for genetic technologies were that they contribute to reducing inequality in society and that regulation is effective without stifling new developments. People are fearful of being kept from knowledge about new developments, society not keeping up with technological change and as a result regulation being inadequate for the purpose. Chapter 2 of the report ends with a commentary on participant views of using genetic technologies as part of a package of solutions to address global challenges, a concept with which there is much agreement amongst dialogue participants and a representative sample of the UK population as tested through the national survey.

## Frames and contexts that moderate public acceptability



Cost



Individual  
Welfare



Collective  
Welfare



Environment



Regulation

In chapter 3 of the report the frames and contexts that moderate public acceptability of developing UK research into genetic technologies are analysed. The findings are drawn from participants' discussions about the case studies in the dialogue sessions and specific comments made during the roving ideas storm in round 2 on what is acceptable and unacceptable for society using cost, individual welfare, collective welfare, environment and regulation as the frames through which discussions are filtered.

An analysis is given of views common to all uses of genetic technologies in humans, plants and animals. The acceptance of which are summarised as those applications which:

- Promote equitable access to genetic technologies as they are developed
- Prioritise collective welfare
- Enable the science to develop further and knowledge of future applications be extended
- Provide cheaper health interventions
- Prioritise positive and reduce negative environmental impacts



- Have benefits to society that outweigh risks to human health, animal welfare and the environment
- Alleviate suffering
- Use transparent processes.

And applications which are unacceptable as being those which:

- Edit out difference and create a monoculture
- Prioritise individual and/or corporate wealth
- Drain currently over-stretched NHS resources
- Enable humans, plants or animals to be weaponised
- Are introduced with insufficient safety monitoring or measures
- Restrict freedom to choose whether they should be applied or not, e.g. enforced genetic screening
- Reduce biodiversity or harm the ecosystem and related food chains
- Contaminate plants or animals not grown or reared using genetic technologies
- Are not sufficiently regulated and equally are so over regulated as to stifle scientific progress.

The survey findings picked up on in this chapter demonstrate that respondents are broadly in agreement with dialogue participants on the frames and contexts that moderate acceptability. The chapter therefore gives a detailed analysis of the commonalities and differences in attitudes and views depending on the application grouped into the five frames listed above, beginning with cost.

Chapter 3 speaks of the difference in findings depending on age, the analysis finds that older segments are more in favour of stricter control of genetic technologies than those who are younger in the population.

## Applications and uses of genetic technologies

In this chapter a comparison is made on the range of views on applications and uses of genetic technologies as applied to humans (London), animals (Edinburgh) and plants (Norwich). The findings are drawn from the survey results and discussions provoked by a review of the case studies selected on each of the three applications (see Chapter 1 figures 4 and 5) held to some extent in round 1 but for the main part in round 2 of the dialogue.

In **human applications** the case study on testing for genetic disorders raised comments around the following four main headings which are explored in the chapter: managing expectations; communicating the results; providing mental health support; and data protection and confidentiality. In discussing the case study regarding non-heritable genome editing for medical treatments dialogue participants focused on achieving a mindful balance in decision making; an ethical and honest approach; setting trends for medical advances; and balancing individual and societal needs.

The main concern raised in the context of the third case study about genome edited human embryos was the issue of consent. The prospect of individuals making genetic choices that would influence all future generations was seen by many as both an opportunity and a threat. An opportunity to free future generations from a debilitating condition, such as cardiomyopathy, or as a threat to the right of the individual to choose for themselves. Dilemmas around consent included the impact on

grown-ups and their offspring of not having had a say in the decision. The finding for survey respondents was somewhat different in that more felt very or somewhat positive towards using genome editing to correct a genetic disorder whether the correction would be inherited by any children of that person or not.

In applications to **animals** participants and survey respondents were supportive of using genetic technologies on animals to prevent or cure human disease as long as any potential side-effects to patients are understood; NHS spending is fully justified; and the impact of genetically modified animals on the ecosystem is understood and minimised. There was much less support for the genetic modification of animals for food particularly when the editing is undertaken for the purpose of increasing the efficiency and productivity of meat production. The majority of dialogue participants and survey respondents did not agree with the cosmetic uses of genetic technologies to animals.

When considering applications to **plants** dialogue participants as well as the population sampled in the survey agreed that producing cheaper medicines, which can reach the people that need them quickly, is a positive development for society. They also believed that using genome editing to produce more nutritious crops to supplement dietary insufficiencies is to be welcomed as a route to feeding world populations. Equally using the technologies to protect crops from damage through, for example, late blight was seen as an opportunity to take a global perspective as part of the solution to a sustainable food system. As in other applications the need for effective regulation was stressed as was the desire to prevent cross-contamination with related plants that have not undergone modification. Using the technologies for cosmetic enhancements to plants was not supported.

## Trusted actors

Workshop participants discussed who they trusted to develop, to advise on and to regulate genetic technologies during the afternoon of the round 2 workshops. An analysis of the findings from these discussions is set out in chapter 5.

In all locations university academics and researchers were seen as the most trusted actors to work on/develop uses for genetic technologies. University academics were most trusted as well to advise and inform on genetic technologies, followed by professional networks (for London participants) and Charities, trusts and foundations (for participants in Norwich and Edinburgh). In relation to information and advice the survey findings were somewhat different with the majority seeing university academics, scientists and researchers as most likely to provide trustworthy information and advice on genetic technologies, followed by businesses working or funding research on genetic technologies and government bodies/policymakers.

The reasons for these rankings are explored in the chapter as being principally:

### More trusted when the actor:

- Is the source of unfiltered knowledge
- Demonstrates impartiality and independence
- Has academic rigour and works within an ethical framework
- Has dedicated their life to science not profit

- Draws on intelligence, years of experience and specialist knowledge
- Works for the global good and is connected to real world challenges.

#### **Less trusted when the actor:**

- Is motivated by profit
- Demonstrates a lack of transparent process or scrutiny
- Is perceived to be less well regulated
- Can be influenced by where the funding for the research comes from
- Is slow, or does not act in the public interest.

The chapter closes with an analysis of the consensus reached in all dialogue groups in each location that some form of multi-disciplinary panel or commission should regulate genetic technologies. A variety of ways of achieving this were suggested with the principle point being made that genetic technologies will affect everyone's lives and therefore regulation should draw on everyone's views. They felt the panel proposed should include all stakeholders including the general public as informed citizens.

## **Impact of the dialogue process**

In chapter 6 we report on observations made by the HVM team in participants' increasing interest in genetic technologies the more they learned about their history, the different techniques and the (potential) applications.

The evidence received by participants, contribution of the expert witnesses, discussion with their peers and the dialogue process itself all allowed for people to shift in their perspectives, becoming more open to discussing aspects of genetic technologies which may previously have been completely unknown to them.

HVM observed participants moving along a learning curve from:

- Not knowing anything at all to feeling they would be more aware of/ interested in the subject in the future
- Fear to cautious optimism
- Thinking that this was another tick box consultation exercise to considering that their voices have been heard and will be of value in shaping the future direction of the work of the Royal Society in engaging the public in science.

When comparing the hopes and fears expressed in round 1, with the views about acceptability and unacceptability when developing genetic technologies in round 2, five shifts in participants' thinking were noted. These are explored in the chapter under the following headings:

1. An increasing sense that regulation that is too oppressive can inhibit progress
2. A need to understand the cost impact of genetic technologies for the UK and global economy
3. Genetic technology is here and developing fast, how do we balance it with other interventions?
4. The risk of large corporations overly dominating the health and food sectors
5. Thinking about what future generations will say about the decisions made now on genetic technologies.

The chapter ends with a number of surprises that participants reflected on in their exploration of genetic technologies. Their first surprise was how little they knew about genetics and associated technologies. A second surprise, linked to the first, was the wide range of opportunities on every aspect of modern life around the world that could be affected by developments in genetic technologies. Thirdly participants were taken aback by how far science has progressed since the 1950s with the discovery of the structure of DNA. In all locations, but most vocally in Norwich, people were initially astonished to find that there is no global regulatory system for the monitoring and approval of genetic technologies. The final surprise referred to in the chapter is that the Royal Society took such serious steps to genuinely engage the public on these issues.

## Conclusions

The report comes to a set of five conclusions drawn together in chapter 7.

### 1. Cautious optimism for genetic technologies in society

HVM concludes from the qualitative and quantitative elements of the research that there is a cautious optimism in society for genetic technologies and their uses. This was validated in the national survey in which 24% of the respondents indicated they are very interested in genetic technologies and 46% fairly interested (see figure 7). 32% of respondents were very interested and 48% fairly interested in scientific developments to address global challenges including climate change, disease and famine. In the dialogue support was particularly high for the use of genetic technologies to improve human health, reduce global inequalities and reduce or help reverse the impact of climate change.

### 2. Caveats for support of genetic technologies

Discussions in all locations showed that caveats for public support of genetic technologies were similar whether related to considerations about human, animal or plant applications:

- The need to focus on essential solutions that enhance society
- Genetic technologies should be considered as part of a package of solutions for global challenges
- There should be equity of access to the technologies
- The principle of ‘no harm to the environment/ecosystem’ must be applied
- Importance of managing expectations
- Animal welfare standards must be maintained
- Information must be accessible, and available to the general public
- Effective regulation, legislation, and ethical guidance must be put in place.

### 3. Opportunity to inform the public about genetic technologies

The survey tells us that 28% of the population had seen, read or heard (on the news, in a paper or on social media for example) information about genetics or genetic technologies in the last month. This is in line with findings in the dialogue (see section 6), where many participants didn’t know much about the subject at the start of the process. This shows there is a huge opportunity to inform the public about genetic technologies and their uses.

#### 4. Updating the genetic technologies narrative

The public dialogue demonstrated that support for applications to reduce societal inequalities, to prevent and cure disease in humans, and in steps to combat climate change are leading to a shift in attitudes towards genetic technologies, which were previously best known for their application to plants and animals for food. This means that there is a real opportunity to update the genetic technologies narrative and have a more informed conversation with the public about genetic technologies and all of their potential applications as part of a package of solutions to unprecedented global challenges. This will be valuable to ensure that this technology can be used to deliver public goods in a manner which has public confidence and builds on the desire shown by participants in the dialogue for science to advance and keep society moving forward.

#### 5. The future for engagement on genetic technologies

To conclude, HVM believes that the Royal Society has created a safe space in which to explore the complex landscape of genetic technologies, from ethical considerations to practical applications and the actors in the field to trust in working and advising on these technologies. Building on the findings we recommend that this safe space continues. This could take a number of forms including:

1. Publishing a Royal Society response to this report demonstrating that the voices of those involved, particularly dialogue participants, have been heard
2. Encouraging those campaigning in the field of genetic technologies to work with the Royal Society to engage the public in a balanced discussion of the issues involved
3. Using the resources developed as part of this public dialogue to devise mechanisms, based on dialogue methodologies, for various communities to take up their own discussions and create their own safe spaces to explore the potential risks and benefits of genetic technologies
4. Continue to engage the public meaningfully by talking publicly about the issues that people care about such as health, the environment, climate change mitigation and addressing global inequalities.



**Hopkins Van Mil**  
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# 1. Introduction to the study

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## 1.1 Scope of the research

This public dialogue study sits within the wider Genetic Technologies Policy Programme (the programme) being run by the Royal Society. It was initiated following the Royal Society's President's speech at the American Association for the Advancement of Science annual meeting in February 2017<sup>1</sup>, which explored the recent scientific developments that have made understanding and adapting genetic material faster, easier and cheaper, with the result that some previously theoretical uses of genetic technologies are becoming increasingly practicable. As well as considering what now can be done, scientists and society must also consider what should be done, hence the Royal Society's programme and this research study.

In July 2017 the Royal Society commissioned Hopkins Van Mil (HVM) to run a public dialogue to explore the range of views that individuals hold concerning which potential applications for genetic technologies should be developed, why, and under what conditions. HVM designed and delivered a two stage process comprising an initial deliberative public dialogue followed by a nationally representative survey of the UK population.

The aims of the dialogue included:

- Exploring commonalities and differences in attitudes depending on applications and the source of the change introduced
- Identifying the problems that people feel genetic technologies are well placed to solve as well as the areas in which they would prefer greater emphasis be put on other solutions
- Identifying the frames and contexts that moderate the public acceptability of developing UK research into genetic technologies, e.g. UK competitive advantage, individual and collective welfare improvement, and environmental improvement
- Identifying who is trusted to work on particular technologies or applications, why, and with what implications, e.g. public vs. private researchers, for profit vs. not-for-profit commercial organisations.

The aim of the survey was to demonstrate the prevalence of attitudes identified through the workshops. Expected outcomes included:

- Clarity on the applications that a majority of the public do or do not support, why and under what conditions
- Clarity on the processes that enjoy public support e.g. cisgenic vs transgenic modification
- Clarity on which actors are trusted to work on which applications
- Clarity on any benefits, e.g. cost, safety, efficacy, that the public feel should be considered alongside the risks.

In both the dialogue and the survey, the discussion focused on the applications set out in figure 1.

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<sup>1</sup> Ramakrishnan, V. [A new age of biology based on genetic technologies?](#) Feb 2017  
Facilitating engagement to gain insight  
[www.hopkinsvanmil.co.uk](http://www.hopkinsvanmil.co.uk)



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## Norwich

- The application of genetic technologies to plants and microorganisms, including as sources of food, medical compounds or raw materials

## London

- Near to medium-term future (0 – 10 years from the present) scenarios for the application of genetic technologies to humans, including heritable and non-heritable interventions for both the treatment and prevention of disease and disability and the enhancement of traits and abilities

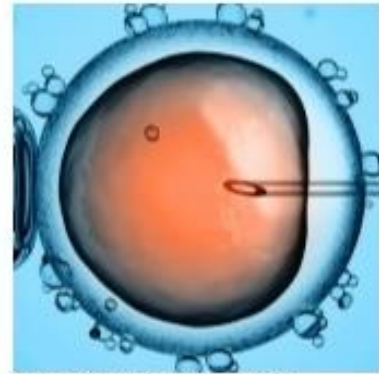


Photo credit: Koya79/iStockphoto



Photo credit: Ingrid Taylor/ creative commons

## Edinburgh

- The application of genetic technologies to animals, including animals as pests, sources of food, companions and wild creatures

Figure 1: Focus of the discussions in each location

## 1.2 Project governance and delivery

The public dialogue and survey were designed and delivered in a co-production process managed by a project team comprising staff from the Royal Society and led by the Chair of the Contact Group which is steering the overarching Royal Society Genetic Technologies programme. The Project Team is set out in the table below, together with the expert witnesses and observers who attended the public dialogue sessions to act as a resource for participants by giving contextual presentations and answering clarification questions.

<b>Project Team</b>		
<b>Name</b>	<b>Organisation</b>	<b>Role</b>
Robin Lovell Badge	Francis Crick Institute	Chair, Contact Group Royal Society Genetic Technologies Programme
Jonny Hazell	Royal Society	Senior Policy Adviser
Tracey Hughes	Royal Society	Head of Marketing and Public Engagement
Emma Woods	Royal Society	Head of Policy
<b>Dialogue Expert Witnesses &amp; Observers</b>		
<b>Name</b>	<b>Organisation</b>	<b>Dialogue location</b>
Françoise Baylis	Dalhousie University	London Rounds 1 & 2
Robyn Butler	Royal Society	Norwich Round 2
Sarah Chan	University of Edinburgh	Edinburgh Round 1 Norwich Round 2 London Round 2
Katie Gearing	Royal Society	Norwich Round 2
Bill Hartnett	Royal Society	London Round 1
Jonny Hazell	Royal Society	Norwich Round 1 London Rounds 1 & 2 Edinburgh Round 2
Tracey Hughes	Royal Society	London Rounds 1 & 2
Ottoline Leyser	University of Cambridge	Norwich Round 1
Xiuju Li	Chinese Association of Science and Technology	Edinburgh Round 2
Robin Lovell Badge	Francis Crick Institute	London Rounds 1 & 2 Norwich Round 2
Lesley Miles	Royal Society	Edinburgh Round 1
Kate Millar	University of Nottingham	Edinburgh Round 2
Johnathan Napier	Rothamsted Research	Norwich Round 1
Youliang Peng	Chinese Association of Science and Technology	Edinburgh Round 2
Dale Sanders	John Innes Centre	Norwich Rounds 1 & 2
Helen Sang	The Roslin Institute	Edinburgh Round 2
Alekos Simoni	Imperial College London	Edinburgh Round 1
Delphine Thizy	Imperial College London	Edinburgh Round 2
Bruce Whitelaw	The Roslin Institute	Edinburgh Round 1
Emma Woods	Royal Society	Norwich Round 2 Edinburgh Round 2
Yijian Yao	Chinese Academy of Sciences	Norwich Round 2

Table 1: Project team, expert witnesses and observers

In addition to input from the Royal Society project team and expert witnesses at the dialogues, HVM conducted a set of depth interviews with ten stakeholders working on research, ethical and sociological aspects of genetic technologies. These are acknowledged in appendix 1 of this report. These interviews were invaluable in scoping the design for the sessions ensuring that a range of perspectives on genetic technologies were taken into account as the sessions were developed.



## 1.3 Participant recruitment

Recruitment for the dialogue was conducted through HVM's fieldwork team against a specification drawn up by HVM and agreed by the Project Team. Our aim was to recruit 90 for 84 participants (to allow for people dropping out) across the dialogue with between 26 and 30 being recruited to take part in the round 1 and 85% retained for round 2 sessions in each location. 100% of the population sample was drawn from a broadly representative demographic of society. Within that we aimed to recruit 10% of people who have a specific interest in the application of genetic technologies under discussion to ensure it was an inclusive process encompassing a wide range of views on the topic. It was made clear to all those being recruited that all three applications were under discussion (human, animal, plants and micro-organisms) during the course of the dialogue but that to ensure a depth of discussion on each application one would be focused on specifically in each location. This is illustrated in figure 1.

HVM devised a detailed recruitment questionnaire and screener (see appendix 2). Once approved by the Project Management Team, the recruitment specification was put into the field using their network of fieldworkers and a panel approach, the combination of which enabled the team to meet the recruitment criteria. The approach was tailored to the selected location before implementation so that it broadly mirrored the demographic for the population in that area.

By means of the screening process, we excluded participants who regularly attend focus groups or market research programmes as they may not be objective about the process, or have 'participant fatigue' meaning their involvement in the dialogue is not effective or representative of their demographic. HVM aims not to recruit friendship pairs or to have snowball recruitment (where one participant invites another).

HVM follows the Market Research Society Guidelines for qualitative research and the Economic and Social Research Council's Framework for Research Ethics (2015). As such we pay incentives for participants involved in dialogue sessions as a recognition of their time whilst not compromising the principle of freely given and fully informed consent. In this case we offered an incentive payment of £160 for attendance at both sessions. To aid participant retention £60 of the incentive was paid at the end of round 1 with the remainder paid at the end of round 2.

Recruitment for the quantitative survey was based on the premise that the results must provide robust statistical insight in to the:

- Applications that a majority of the UK public support and why
- Processes that enjoy public support e.g. cisgenic vs transgenic modification
- Trusted actors to work, provide information and advise on genetic technologies
- Benefits that the public feel should be considered alongside the risks.

HVM ran a nationally representative survey of 2,000 UK adults aged 18+, excluding those with a professional stake in genetic technologies (e.g. clinicians, academics and policy makers in the field). The survey took 20 minutes to complete and was conducted online. Participants were recruited via an online panel. HVM ensured that the sample included those aged 75 or over as an online survey can be a deterrent for this age group. If that had been the case here HVM would have conducted a

number of telephone surveys to ensure this age group was included. However, online respondents included a good spread of ages from 18 to 98 years of age, with over 10% being in the 75+ age group, so the telephone surveys were not required. Within the timeframe proposed, this approach offered the most robust and cost-effective means of delivering the representative sample and the breadth of insight the Royal Society required to inform the programme.

## 1.4 Methodology

HVM convened three groups of 26-29 people who participated in two rounds of workshops with a gap of three weeks between the two rounds. The groups were convened in Edinburgh, London and Norwich and considered one of the three applications as set out in figure 1.

### 1.4.1 *The process*

A two-round process is a fundamental element of a deliberative public dialogue. It allows participants, the facilitation and project teams the time to reflect on what is being said and understood, and work flexibly in response to that. It encourages people to think beyond the first thoughts they may have had in the first round and, in response to a variety of evidence based stimuli, engage in the subject with a depth of thinking so important to a subject rich in technological, ethical, social and regulatory complexities. An example of the process plans for each dialogue round is included at appendix 3 of this report. The same process was used in each location, with changes to the case studies used depending on the application under consideration.

Before attending the dialogue all participants were sent joining instructions in the form of the programme for their first workshop and a 'points to help the discussion' document (appendix 4). This is an important point of reference for participants. The aim is to make roles and expectations clear so that participants are not too daunted by the process before they arrive. The document also explains the pre-task set before coming to the first workshop which was that they were asked to attend the session with notes they had made, press cuttings they had found or simply memories of something they had heard, read or seen on genetic technologies to discuss at the workshop. These materials were used in the first warm-up session of the dialogue. The discussion on them allowed the facilitation team to gain a sense of what people knew about the subject before the discussions began in earnest, and to demonstrate to everyone the range of genetic technology applications that could potentially be under discussion.

### 1.4.2 *Dialogue materials*

Participants were divided into three small groups in each location. The small group allocations were formed by ensuring that one of the three people who had said in the recruitment process that they had a specific interest in genetic technologies was placed in each group, after which participants were selected so that each group reflected the broad demographic recruited. Participants stayed in the same group for both workshops to ensure that trust was built and people were comfortable in expressing their views. The groups were run by an HVM facilitator, with a Lead Facilitator managing the whole session. The same facilitator stayed with the group they were allocated with in round 1, again to support the rapport being developed, an essential part of the dialogue process giving people confidence to interact with each other, their facilitator and the expert witnesses as equals all bringing rich lived experience to the process. Another factor to note was that the same three

senior HVM facilitators worked at all three locations ensuring a continuity of approach and for each session to inform the next.

For the round one dialogue workshop the Royal Society and HVM, working in co-production, devised a range of stimulus materials (see appendices 5-7):

- A **talking heads video**, produced by HVM, introducing participants in each location to the purpose of the dialogue, the value of hearing the views of the public on the uses of genetic technologies and an explanation of what the Royal Society would do with the findings once published
- A **jargon buster** defining the terms likely to come up during the course of the discussion which was used throughout the process providing clarity and a resource on which participants could draw when discussing a specific aspect of genetic technologies
- Equally valuable in terms of answering the question, ‘when did humans first..?’ was a **timeline** of genetic technologies research and controversies which helped to explain what had happened over time, starting with the earliest selective breeding of animals and plants right up to present day innovations coming along with increasing rapidity after the discovery of the structure of DNA in 1953.

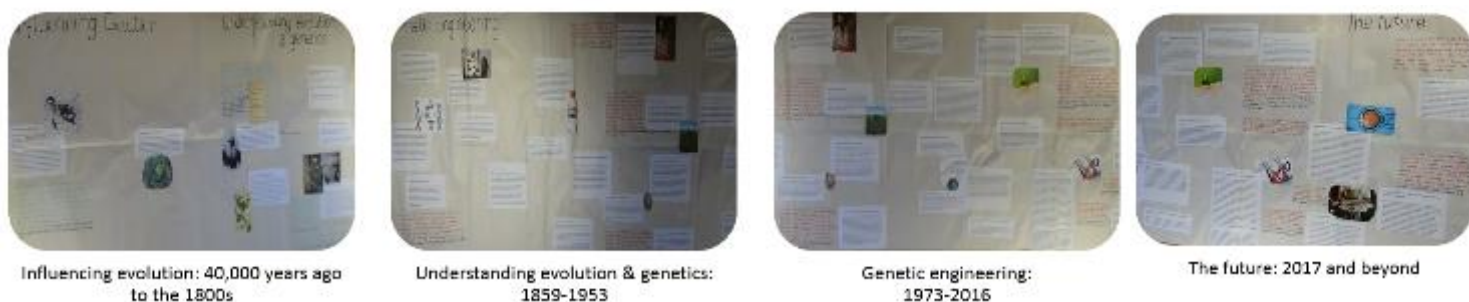


Figure 2: A snapshot of the timeline

Additional material was added to the timeline for round 2 in response to participant queries on the legislative framework for genetic technologies in round 1. Dates were added to the timeline citing when key pieces of UK, European and international legislation were enacted. In round 1 a **contextual presentation** was delivered by Royal Society staff including an animation<sup>2</sup> developed by the Society with the Wellcome Trust on genome editing. Most materials were given to participants in hard copy on arrival at the session within a printed participant pack. The timeline was the exception as it was created graphically with printed text giving the key pieces of information and hand-written text providing contemporaneous quotes in line with the developments being described. These were included to show that there are a range of views on any new developments in genetic technologies. The timeline was displayed in the dialogue discussion space so that participants could review it in the breaks, refer to it in small group discussions and add their own comments to it using post-it notes which were then stuck to the timeline (see figure 2).

For round 2 HVM interviewed to camera Patrick Holden, the Founding Director of the Sustainable Food Trust and Sarah Chan, an expert witness to the dialogue who is Chancellor's Fellow at the Usher Institute for Population Health Sciences and Informatics, University of Edinburgh. This footage was edited together with an existing clip from Kumi Naidoo, Director of Greenpeace International.

<sup>2</sup> <https://royalsociety.org/topics-policy/projects/genetic-technologies/>  
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The purpose of this second **talking heads video** was to present a range of views on the use of genetic technologies including from scientists, NGO representatives and ethicists. The round 2 **contextual presentation** presented by Royal Society staff focused on the post-1970s development of genetic technologies and current regulatory frameworks for the technologies.

The material in the participant packs for each round was introduced to participants early on in the session as part of each of the contextual presentations and in the initial stages of the small group discussions. In round one all participants worked with a specific case study. Each related to the focus of the discussion in their location as set out in figure 3.



Figure 3: Summary of round 1 case studies

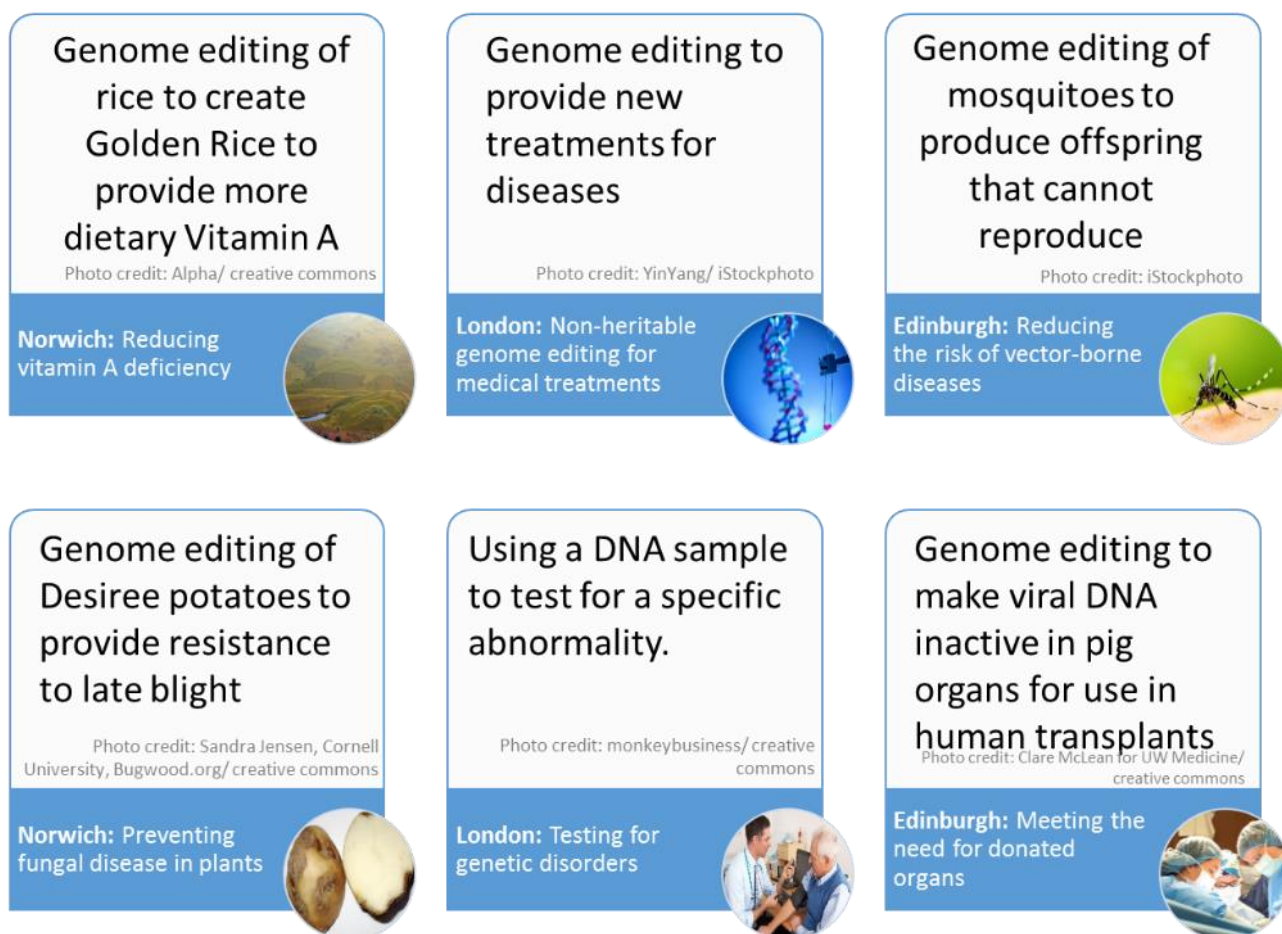


Figure 4: Summary of additional round 2 case studies

In round 2 a further two case studies were added to the packs so that each small group worked on one specific example. This meant that one group extended the discussions they had in round 1 on the initial case study and the other two groups focused their discussions on the case studies set out in figure 4. The description of each case study includes the title of the case study in the bottom blue box and the global challenge or context for that case study in the white area above.

Case studies gave participants concrete examples on which to base their discussions throughout the session. In both rounds the team sourced quotations from NGOs, scientists, social commentators and from media sources providing a range of views on the use of genetic technologies. In round 2 news clips were shown to participants which describe the genetic technologies and provide a further commentary on their use.

Participants in each round at each location were further supported by having witnesses and observers (see table 1) with them at each workshop to provide further information, answer questions and reflect on emerging findings as required.

### *1.4.3 Recording the dialogue*

It is important that the discussions are recorded effectively so that what people say can be transcribed and used for data collation and analysis. At the beginning of the dialogue process participants are clearly told that the things they say will not be attributed to them in either the transcription or the final report as we are interested in what people say, not who said what. HVM uses five main recording methods:

- Audio recording of each small group and the plenary sessions - these recordings are transcribed in summary after each workshop
- Flip chart recording by the facilitator who notes the key points made and themes arising – these are transcribed in bullet point noting all the points and themes
- Post-it notes used by participants to record thoughts and headline points in their own words – these are transcribed as part of the flip chart transcription process.
- Participants were asked to create posters of their thinking in round 2 to produce visual records of key points – these are reported on in chapter 4 of this report
- In addition some participants were filmed to camera on their thoughts about the dialogue process - clips are integrated into this report.

### *1.4.4 Round 1 summary*

The round 1 workshops were held in the early evening to ensure that people could commit to this contextual session with all their concentration and energy. Sessions began at 6pm and ended by 9.15pm. At the beginning of the session the HVM Lead Facilitator presented an introduction to the dialogue, reminding people of the points made in the joining instructions, and the initial talking heads video was played. Participants then moved to their small groups and took part in the warm-up discussion previously described. This led on immediately to a discussion of the big issues facing society. Once participants had a list of all the challenges they felt were being faced they discussed the relationship of genetic technologies to them. Quite deliberately this section of the dialogue took place before participants had received any detailed information on genetic technologies or had a chance to explore the case studies to get a feeling for how genetic technologies are perceived when

considered within the broad span of global challenges and get an initial feel for what people find (un)acceptable before receiving contextual information. The findings of this discussion are set out in chapter 2 of this report.



Following the contextual presentation and the introduction to the timeline and case study participants spent time in their small groups working on the questions and comments they had on this material. Each group then summarised this discussion by coming back to the

plenary with the two most important points that they wished to raise with the expert witnesses. In a reflective process the facilitation team find it more valuable to give people time to reflect on the questions and points they wish to make in a plenary session rather than asking the first points that come to their minds in a question and answer session immediately following a presentation. The second reason for this was to give an opportunity for participants to ask for the jargon buster to be updated with more information on the words or phrases they didn't understand or needed more explanation. These questions led to a very fruitful interaction between the expert witnesses and participants which continued throughout the dialogue.



In the next session participants explored their hopes and fears for using genetic technologies in relation to either humans, animals or plants and microorganisms depending on the focus of the discussions in their location. Facilitators built on these discussions by exploring what participants perceived to be the opportunities, risks and uncertainties in relation to genetic technologies. This session ended with a discussion on the alternative solutions that might be used to address the global challenges they had raised earlier including solutions which are:

- Technological
- Social
- Political
- Economic
- Ethical
- Regulatory.

Round 1 ended with a final plenary in which each small group presented the two main findings from their discussion and the expert witnesses present gave their reflections on what had been discussed during the evening. Next steps were explained and participants were given a task to complete before they attended the round 2 workshop.

#### *1.4.5 Round 2 summary*

As an important part of the deliberative process HVM allocated a break of two to three weeks between each dialogue round to enable participants to think further about what they had heard

and discuss it with friends and family. HVM used a formal process to encourage these discussions asking each participant to interview at least two people by reporting back what they had heard in the round 1 discussions and asking their interviewees to respond to it. This space for reflection is also beneficial for the facilitation and project teams who were able to think about the headline findings that had emerged from the round 1 discussions and assess the extent to which changes were required to the round 2 process. Here are one participant's view on enabling reflection time.

Round 2 workshops were held on a Friday in London and Saturdays in Norwich and Edinburgh. They lasted from 10am to 4pm with breaks and lunch provided. A welcome presentation was again given by the Lead Facilitator for each location. This reminded people of methods of working in dialogue sessions and set out the programme for the day. Participants then returned to the small groups they worked in in round 1 to discuss the interviews they had conducted with friends and family during the break from the dialogue. Then followed the talking heads videos and the contextual presentation so that participants were clear that a range of views are held on the uses of genetic technologies and given information on developments in the field since the 1970s and the legislative framework under which genetic technologies are developed. As in round 1, participants returned to their small groups to formulate questions for the panel of speakers and expert witnesses which were then discussed in a plenary session.

In the next section of the workshop participants were asked to imagine that they were at a meeting attended by a range of actors in the genetic technologies field. The actors used in this session are set out in figure 5. The purpose of the meeting was to discuss the case study. Each participant was asked to assume the role of one of these actors selected at random but so that all of the actors were covered within the group. They were asked to think as they thought a person in that situation would think and consider the next steps for society in relation to this use of genetic technologies as set out in their case study (see figures 3 and 4). They were asked to consider the ethical, social, technological, environmental and regulatory aspects which need to be taken in to account, and also to think of solutions not involving genetic technologies which they could employ to achieve the same outcomes.

Participants were first asked to write their thoughts on post-it notes. These were collated on a flip chart by the facilitator and then the participants were asked to work together, or in two smaller groups, to create a visual representation of the press statement they would make to the media explaining the meeting's deliberations. This discussion concluded with participants presenting their visual statements to the whole group in a plenary session.

Using a fast-paced roving ideas storm method, the session after lunch required participants to walk around the dialogue space and comment on four themes that had been set out on flip chart paper around the room. These were:

- Cost
- Individual welfare
- Collective welfare
- Environmental impact.

Each group, working with their facilitator and bearing in mind their group's case study, went to each themed area in turn where they were asked the same two questions:

**Q:** What in your view is acceptable for society in terms of this theme and our location's focus?

**Q:** What in your view is unacceptable for society in terms of this theme and our location's focus?

The aim of this was to test participants' tolerance to genetic technologies when considered from various perspectives because what might be completely acceptable for individual welfare, for example, might be completely unacceptable for its impact on the environment or in terms of cost. Facilitators pushed participants to give as full a response as possible under each theme.

In the last section of the day participants, again working in their small groups, returned to a consideration of the actors operating in the field of genetic technologies. In this session the groups were asked to rank cards with the actors printed on them (see figure 5). The first ranking was to test which of the actors they would most trust to work on, or develop uses for, genetic technologies.

Participants used sheets to rank a sub-set of the full list of actors from 1-4 with 1 being most trusted:

- Businesses working in genetic technologies
- Charities, trusts and foundations
- Privately funded academics, scientists and researchers
- University academics and researchers.

This ranking exercise was conducted a second time asking participants to consider which of the actors they would least trust to work on or develop uses for genetic technologies. Following these two rankings the facilitators drew out participants' views on why they had ranked in the way that they had. A second ranking exercise was then conducted asking firstly which of the full list of actors in figure 5 they would trust to advise and inform on genetic technologies and then which they would least trust to advise and inform. At the end of each ranking participants were asked to turn over their sheets and not refer to them when deciding on their 'least' choices. It was important to do this, to conduct the ranking four times and to really probe how and why participants ranked the



actors, to explore effectively the issue of trust in those working, developing, advising and informing on genetic technologies.

The end of the day had two components. After the ranking exercise participants were asked to consider their rankings and in the light of that reflect on who they would trust to regulate genetic technologies. Participants were then asked to summarise their discussion on trust into two main

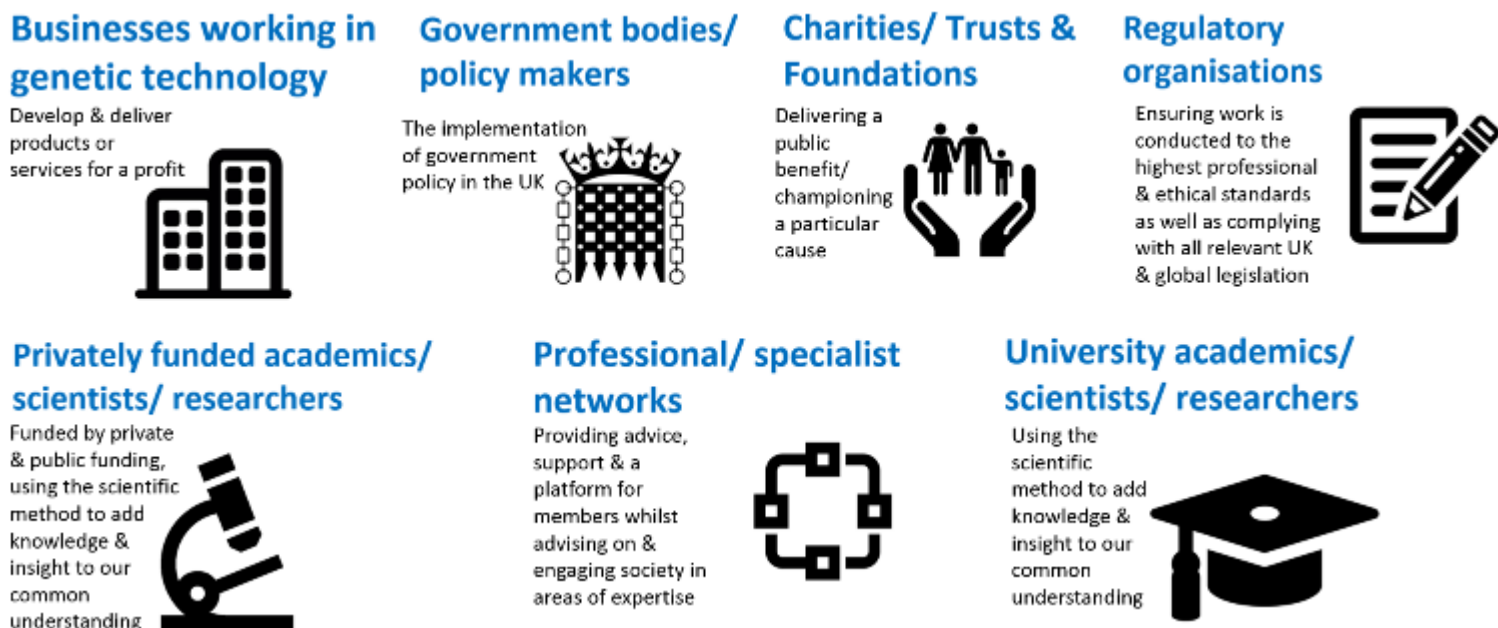


Figure 5: Actors in the field of genetic technologies

findings which were presented by each group to the plenary session. The expert witnesses present at each session reflected on all they had heard during the day. The Royal Society staff present and the facilitation team ended the session with a warm thanks to participants for contributing their time and energy so fully to the dialogue process, and by giving an explanation of steps towards the publication of this report. Participants were assured that the report would be sent to them in due course so that they could see how their views had translated into findings for the Royal Society.

#### 1.4.6 The survey

A quantitative survey was designed in the light of the interim findings of the dialogue. Its purpose was to validate those findings by asking questions of a representative sample of 2,061 adults across the UK using a panel approach and engaging all participants online. The confidence or significance level for this study is 95% meaning that we are 95% certain that the quantitative findings represent the views of the UK population. There is a  $\pm 5$  confidence interval meaning that for any percentage figure given, 5% less or 5% more in the whole UK population might have responded in the same way. The 48 survey questions covered attitudes towards genetic technologies in general as well as attitudes towards specific applications. For the main part we have noted no significant difference in how respondents answered the question in terms of their age, gender or other demographic factors. Where significant differences are evident between the qualitative and quantitative data or in the demographic factors these are highlighted in the chapter narrative. The survey took 20 minutes to complete and the questionnaire plus main survey data is included in appendix 8. Demographic data are also included in appendix 8 and the technical note accompanying it explains how these data were used in the analysis. Fieldwork took place from 1<sup>st</sup> to 13<sup>th</sup> November 2017.

## 2. Genetic technologies and global challenges

### Chapter 2 summary

In this chapter we explore participants' views on global challenges, the potential role of genetic technologies in finding solutions to those challenges, and alternative solutions that were highlighted as the discussions unfolded. This is combined with an analysis of people's hopes and fears around genetic technologies. Participants were prompted to discuss the significant global challenges faced by society in the first warm-up discussion of round 1. They raised a significant number of challenges which the report authors have grouped into the broad themes set out in figure 6 and which provide the framework for analysis for the first part of the chapter.



Figure 6: Summary of global challenge themes

One participant summarises some of the global challenges in the following vox pop:

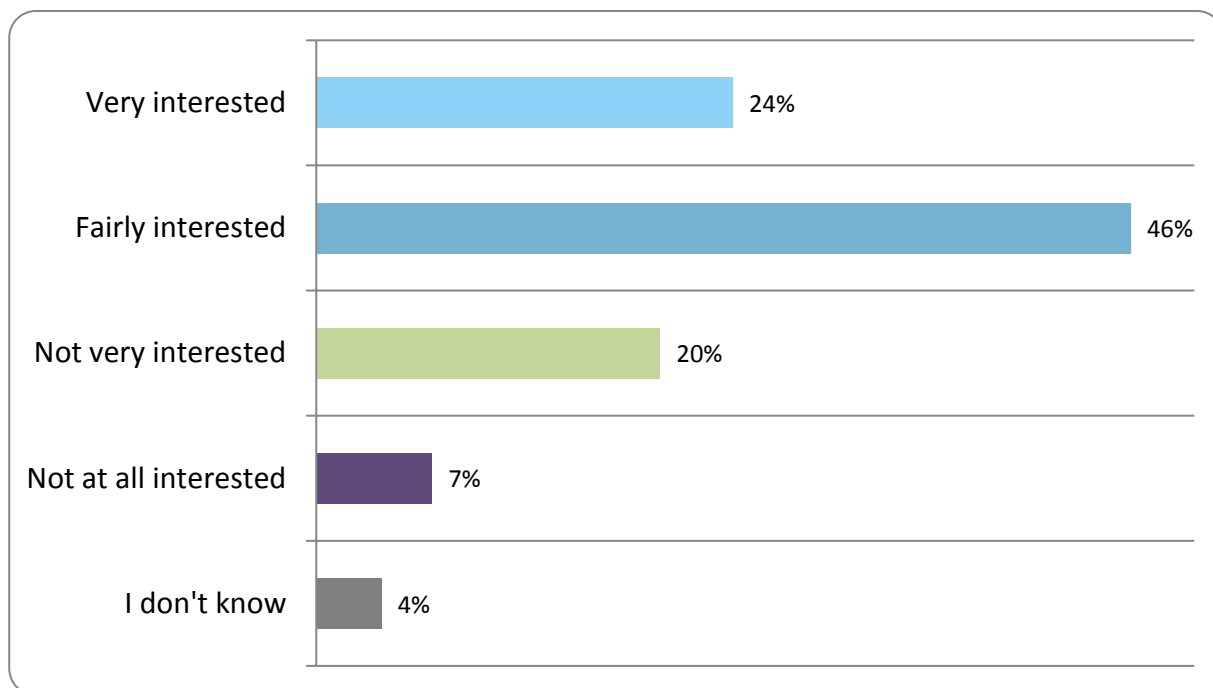


The hopes and fears for genetic technologies raised by participants having heard the initial contextual presentation on *A History of Genetic Technologies* are integrated into this chapter. The principle hopes for genetic technologies were that they contribute to reducing inequality in society and that regulation is effective without stifling new developments. People are fearful of being kept from knowledge about new developments, society not keeping up with technological change and as a result regulation being inadequate for the purpose. Chapter 2 of the report ends with a commentary on participant views of using genetic technologies as part of a package of solutions to address global challenges, a concept with which there was much agreement amongst dialogue participants and the UK population as tested through the national survey.

Initial discussions on global challenges were held in the warm-up session at the start of round 1 before participants had received any contextual information in the form of the presentation or introduction to the timeline and the jargon buster. The hopes and fears discussion was held immediately after these contextual inputs were provided, but the combined analysis gives an indication of people's views before they have engaged in any particular depth on the subject. The quantitative survey findings are included as a further test of the views expressed in the dialogue when compared with a representative sample of the UK public who have only received one input<sup>3</sup> by way of context before completing the survey.

It was clear from the recruitment process (see 1.3) and early discussions on the global challenges relating to genetic technologies that most participants did not feel they had any particular knowledge or understanding of genetic technologies in terms of how they are regulated, what applications they have been approved for, who develops and owns the technology and their potential future impacts. However this lack of knowledge was not a barrier to curiosity about the subject. For example, the majority of survey respondents (70%) said that they were either fairly interested in genetic technologies (46%) or that they were very interested in the subject (24% - see figure 7).

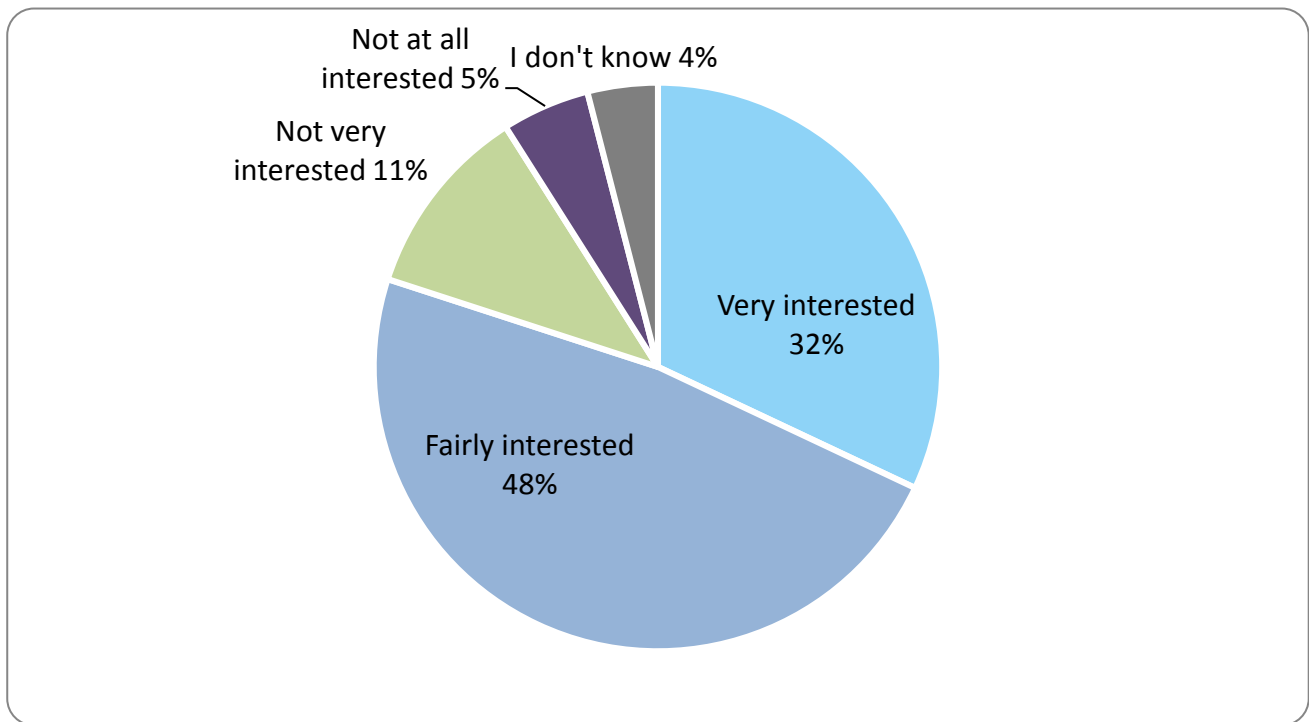
**Figure 7:** How interested, if at all, are you in genetic technologies? (By genetic technologies we mean anything to do with understanding, making or adapting genetic material, but excluding conventional breeding/reproduction).



When asked how interested they were in scientific developments to address global challenges 48% of respondents indicated they were 'fairly interested' and 32% 'very interested', as demonstrated in figure 8 (80% in total). This demonstrates a high level of interest in the UK population on the role of science to address issues such as climate change, disease, famine and overpopulation which were the examples given within the survey.

<sup>3</sup> Royal Society/Wellcome Trust: [What is gene editing and how does it work?](http://www.hopkinsvanmil.co.uk)  
Facilitating engagement to gain insight  
[www.hopkinsvanmil.co.uk](http://www.hopkinsvanmil.co.uk)

Figure 8: How interested, if at all, are you in the role of scientific developments to address those challenges?



## 2.1 Addressing inequality

Addressing inequality was first discussed in general terms as one of the global challenges faced by society. People talked about the challenges of a society in which there are ‘haves’ and ‘have nots’ such as poverty and greed, and excessive profits for big business. They discussed food inequality, obesity and famine. Inequality became a recurring theme throughout the dialogue continuing immediately in the discussion on hopes and fears. People’s principle hope in relation to this challenge is that access to the potential benefits, for example for improving health and increasing food stocks, by using genetic technologies would be available to all, not only the wealthy or privileged. We turn first to financial inequalities.

### 2.1.1 Financial inequalities

In round 1 financial inequalities were considered a substantial global challenge which could easily affect who would benefit from developments in genetic technologies. Participants reflected on the challenge from both a UK perspective, with financial inequalities between deprived and affluent areas of the country, and in terms of financial inequalities between the western world and developing countries. People were fearful that the greed people perceive in some sections of society could filter in to considerations on how genetic technologies could be distributed. More discussions on this in the early sections of round 1 were held in London and Edinburgh than in Norwich. One participant summarised the views of many in these locations,

*‘In terms of greed, I was thinking about wealth distribution. We were talking about how, realistically this kind of technology would only be available to people at the very upper end of society.’* (London)

For other participants inequalities were likely to be exacerbated if the technologies prove expensive. They pointed out that there was another side to the discussion. It was felt that if the technologies became less expensive they could help to alleviate these inequalities. As one participant said,

*'Inequality could go either way. I don't know that it is necessary, but if it is expensive, and it's the people who can afford to pay, let's say it's improving their ability, their health, or their academic or physical performance, then that will increase inequality. If it actually turns out to be relatively cheap, or very quickly becomes relatively cheap it could lower inequality because people who are less healthy, less physically or intellectually able would have a chance to change things. (London)*

For some these financial inequalities present a dystopian view of the future in which the wealthy are able to employ genetic technologies to live longer and create even greater divisions in society,

*'The wealthy brigade can live longer because they'll be able to afford this genetic manipulation. The poor won't be because they won't be able to afford to have the manipulation done to themselves, so you'll have a separation of people.'* (London)

Participants in Edinburgh saw the regulation of genetic technologies as a way of preventing such inequalities. They asked,

*'How can the regulations stop this from being something that only a small number of people can benefit from and something that's a good thing for society?'* (Edinburgh)

Participants saw these financial inequalities in terms of corporations and big businesses and for some there were equally some positives for the economy in those with the financial means accessing genetic technologies. As one London participant said,

*'It could be linked with the financial economy, in the fact that this technology could increase the genetic technology industry. Even though wealthy people would be the ones that would be using it, it could be siphoned back in to the economy which could then use the money in other sectors.'* (London)

All locations discussed the role of big business and corporations in genetic technologies. This is discussed further in the analysis of trusted actors in the field (see chapter 5) and in what is acceptable and not acceptable for society (see chapter 3). In the context of global challenges and the hopes and fears for global technologies, participants discussed the potential for the UK gaining a competitive edge in the field which the majority thought would be positive for the economy and therefore in terms of reducing financial inequalities,

*'Who wants to be first there? Is this a First World thing? Are we going to be top of the tree leading the way? First to take the risks? The Royal Society are going to bring this into focus now. It could change this country anyway, really become a leading light.'* (London)

Participants talked about countries working hard to gain the initiative in the development of new genetic techniques, working within countries to gain an advantage over their competitors so that their own country leads in the field globally. Participants made comments such as,

*'I'm sure there are ways out there, whoever gets hold of this genetic technology or breakthroughs first they will have the competitive edge in the world.'* (London)

Other comments were ambivalent about such a race, comparing it to the Cold War arms race,

*'It's like the new-age nuclear genetic race.'* (Edinburgh)

What some participants saw as an opportunity for others has a somewhat different angle involving global cooperation for a really significant scientific development. One participant summed this up by saying,

*'Can they not share? Why don't we do it together? Why can't this be something humans do differently? Instead of trying to beat each other why can't we do it as one species?'* (Norwich)

Two participants in Norwich echoed the views of many in all locations on the profit motive for larger corporations which they saw as a source of fear in the use of genetic technologies, again creating financial inequalities and restricting the benefits to those who can afford it. They said,

*'Is there a risk that (drive for profit) will happen with major drug companies? If genetic technology can produce something that's going to take away a big profit margin for them will they buy the patent and suppress it so we don't get anywhere with it?'* (Norwich)

*'Many of these things (genetic technologies) sound great, but I think the driver of it is economic. There's a lot of profit to be made for large corporations.'* (Norwich)

And in Edinburgh a participant saw the profit motive as a real challenge. They perceived this to be a fear in relation to genetic technologies as they felt that there had been examples in other sectors, including the pharmaceutical industry,

*'The power that gives these companies for example to dictate food prices. We've already seen the risks of that with pharmaceuticals, people increasing the cost of HIV drugs by 5,000%.'* (Edinburgh)

### **2.1.2 Food inequality**

Participants in all locations spoke of famine, obesity and inadequacies in global food distribution as major challenges to be addressed. Some participants at this early stage in the dialogue made some very big claims for genetic technologies in relation to solving the global challenge of famine and food inequality,

*'GM has the potential to solve world hunger.'* (Edinburgh)

One group in Norwich, before seeing the case study on Golden Rice which was only introduced to the participants in round 2 of the dialogue, discussed food inequality by expressing the hope that genetic technologies could be used to increase the nutritional value of food. One participant commented,

*'We mentioned on the positive side that if you can modify food to increase the nutritional value that would be a good thing so you could feed more people well.'* (Norwich)

This was echoed by a group in Edinburgh in the first plenary discussion of round 1 who made the following statement as one of the three points they wanted to share with everyone in the room. They said,

*'GM food could bring healthy, more nutritious food to those who currently can't access it.'* (Edinburgh)

In a discussion in Norwich one participant pointed out that to enable steps to be made to reduce global food inequalities using genetic technologies, there first needs to be an acceptance of genetic technologies as a method. They said,

*'If we accept genetic technology in crops - we can deal with famine, shortage of food and stuff like that.'* (Norwich)

A participant in London explained that using the technology to increase food stocks more quickly than with traditional farming methods was why this could be considered one of the solutions to a severe lack of food,

*'In famine because they can grow the food more, and quicker.'* (London)

In Edinburgh they discussed this also in relation to meat production. One participant in Edinburgh had done some reading on genetic technologies before attending the session. They could see within this both reasons for hope, in helping countries produce more food stocks, but also fear in that creating food in such a way might have unforeseen consequences for the food chain. They said,

*'I've been reading about food and how genetic technology can help countries that can't feed themselves, developing crops that are more sustainable and bigger yields in terms of meat products. That also runs the risk of creating problems with the food chain and methods around that.'* (Edinburgh)

We see in these early discussions that participants are considering genetic technologies as one of the tools which could help to address both obesity and food security. As one Edinburgh participant commented in the discussion on hopes,

*'We still have billions of people in the world who don't have enough to eat and we have loads of people in the world who eat too much. [We need to discover how] to use the technology in order to ensure that everyone can survive and they have enough to eat in a sustainable way.'* (Edinburgh)

And another raised it in relation to the challenge of an unsustainable, in terms of both health and environmental impacts, over-consumption of meat. They said,

*'There is a big problem with people eating too much meat. Is there a way these technologies could be used to make that less of a bad thing?'* (Edinburgh)

## 2.2 Responding to social change

There were several social factors which were discussed as challenges by participants in all three locations. They raised the challenge that the way people work is changing as a wide range of technological changes are coming into force from machine learning to dramatic digital developments. Comments were made about future employment requirements and patterns as a challenge for society in and of itself. As a participant in London said,

*'The way we work, and how we understand work in the future. It may change.'* (London)

For others the challenge was in relation to the fact that life expectancies are lengthening and they felt that may change the ways in which we work throughout our lifetimes, bringing changes to when we retire for example,

*'We're living longer but we're working longer as well so maybe that balances it out a bit.'* (London)

In the discussion of fears people raised the concern that the introduction of genetic technologies which increase the growth of salmon<sup>4</sup> for example, or speed up the means of production for previously more labour intensive activities might have an impact on available jobs and increase unemployment. A participant in Norwich said,

*'If Canada produce these salmon does that affect the British industry, are we losing jobs?'* (Norwich)

And in Edinburgh,

*'There needs to be things put in place that mean people's jobs aren't completely destroyed.'* (Edinburgh)

This leads to the unprompted discussions participants had on the speed of change in genetic technologies at the beginning of round 1. These gave rise to comments that such fast changes in what is possible in this relatively new area of knowledge might mean that we do not have the ethical frameworks in place to manage the change effectively. A participant in London expressed this fear in this way,

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<sup>4</sup> Edinburgh round 1 case study: *Reducing the negative impact of fish farms*. See figure 4  
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*'It may get to the point where it's out of control. As in, what we see as ethical and what is not. It could be going at a fast pace. Once you've opened a certain door, there's no closing it when it comes to genetic technology.'* (London)

Another participant in a different London group felt that the fear was that the population's understanding of the changes genetic technologies could bring to society would not keep pace with the developments themselves. They said,

*'If the technology moves quicker than people's thinking, the ability to do these things moves quicker than the general population's ability to understand what's going on and to think about it.'* (London)

The ethical and moral frameworks under which society manages all new societal developments was seen as a very important global challenge to be considered. It was raised by participants in all locations throughout the dialogue, but early in round 1 it was a concern expressed more overtly by London participants, perhaps because the focus for the discussions in London was applications of genetic technologies to humans. Participants expressed this partly in the fear that society might lose its moral compass and become more intolerant of difference in a new age of genetic technologies. They saw the potential for a dystopian future with decisions being made about what imperfections, if any, would be tolerated by society and using genetic technologies to weed out the genes which didn't allow people, animals or plants to conform to that what society considered 'the norm'. This caused concern on many levels not least in a discussion of which and whose social norms would be adopted. As one participant in London said,

*'Whose 'society'? We talked about cultural differences, variances, beliefs, it's whose society? Every society is different.'* (London)

Chapter 3 of this report contains analysis on regulation, which is therefore not specifically covered here, but the conversations on ethical frameworks, before participants formally considered regulation are significant as the thinking at this stage in the dialogue informed the points made when regulation was considered. Participants gradually grew into a discussion in the fears section on who should make the ethical and moral decisions which inform the development and use of genetic technologies. The concern was vividly expressed by one London participant,

*'Who decides what bad qualities are? What stops some megalomaniac deciding people of a certain IQ shouldn't be allowed to breed and finding a way to stop them? It's fine saying you've got the good things like getting rid of diseases but you've also got this risk some idiot's going to decide redheads are stupid and we must find a mutation to get rid of them.'* (London)

Participants thought about where the line should be drawn in terms of what is acceptable to society and what is not, and questioned what they would do if faced with a life-threatening illness or other really challenging decisions,

*'We've had so many advances over the years from Leonardo da Vinci to today. Where do we draw the line with ethics in terms of a moral standpoint? Personally I'm all for genetic technologies but even personally, where would I draw the line with it?'* (London)

Participants in Edinburgh questioned whether or not ethical consideration would be taken into account by society as it continues to develop genetic technologies,

*'Is this being done from an ethical viewpoint to solve a solution to something? When can it balance over into potential harm? Where's the tipping point of things once the control is in place?'* (Edinburgh)

One participant with personal experience of a risk of a potential genetic mutation identified during pregnancy, which turned out not to be the case, said,

*'I feel like they're going to try and screen people out and I don't think that's a good idea.'* (Norwich)

Before any in-depth discussion on the London round 1 case study took place a London participant reflected on the point that it is the parents and/or medical profession who could make a decision on genome editing in human embryos, but the decision made to correct a genetic mutation here would have consequences for the child once born. Participants in general felt at this stage in their discussions that they needed more time to think about how they felt about this. As one said,

*'I suppose one ethical factor I don't know how I feel about yet would be if you're manipulating genetic factors before someone is born versus when they're able to make that choice in their own life.'* (London)

This raised the point made by each of the small groups in London that developments in science were pushing at the boundaries of what is possible at an ever increasing pace but that the science cannot be divorced from the ethics involved. They highlighted that this makes the long-term ethical discussions required by society both complex and subtle. As one participant said,

*'It's a huge Pandora's box of ethics. It's not science on its own. There are other moving pieces to this. It's nice to say, 'Yes I can eliminate a certain condition.' But what are the consequences with it? We simply don't have enough information.'* (London)

For this reason participants in the dialogue really welcomed the inputs from the ethicists who joined the dialogue as expert witnesses. As one participant in London said,

*'Having a philosopher on our advice team has really helped supplement the science and that has been a lot of fun.'* (London)

For other participants the ethical discussion involved considerations of religious faith. For example, whether accepting genetic technologies in society would be acceptable at all for some people of faith. These two comments from participants in London and Edinburgh sum up the views expressed,

*'At the moment Jehovah's Witnesses don't even accept blood transfusions, so there might be other things that won't be accepted.'* (London)

*'For me its religion. Was it designed to be this way? You could argue that we're here because we got the brain to make God's will happen but is it God's will? I'm not sure.'* (Norwich)

These ethical challenges have the potential to lead to profound questions about what society will accept. A London participant referred to his recent investigations of his family's history using DNA searches. For him, and a minority of others across the dialogue, this raised the shadow of Nazism which made him concerned that this is an area of science which has such potentially enormous societal implications that it should be approached with great caution. He said,

*'If you look back to the 1930s Adolf Hitler would have found this a great gift. He would have been able to absolutely precisely target who he wanted to and then perhaps change them to what he felt they should be. There are some inherent dangers in it and you wonder whether we should. There are aspects that are so big that can man actually handle them?'* (London)

But the view that society was going to areas that it should not was countered by another view suggesting that some risks are worth taking and necessary for society to take advantage of the benefits and opportunities around significant developments,

*'This could be our new opportunity. We don't know what happens when we choose to do anything. When the humans walked out of Africa they didn't have a map. They just went, 'Let's give it a go.' Those massive migrations made by humans throughout our history, they did not know what they were doing. All they knew was how to do it but they didn't know what would happen in the end.'* (London)

A number of participants saw developments in genetic technologies through the lens of recent political events. Brexit was mentioned in terms of people not relying on experts to inform their opinions and others turned to the US elections for an example. One Norwich participant expressed his fear on this as follows,

*'What worries me, especially looking at the US is the idea that people won't accept the scientific evidence. I think that plays a lot into the MMR and climate change debates that aren't debates at all. I'd hate to see a safe, rigorous product or experiment fall flat because people are sick of experts.'* (Norwich)

## **2.3 Preventing and reversing environmental harm**

Whilst participants in all locations specifically mentioned climate change, pollution, population growth and sustainability across all the earth's systems as key challenges it was in Edinburgh and Norwich, with their focus on animals and plants/microorganisms respectively, where rich discussions on hopes and fears in relation to reversing environmental harm were raised at this initial point in the dialogue. A number of participants, particularly in Norwich, specifically referred to an opportunity they saw for genetic technologies to positively counter the impacts of climate change.

Two participants expressed their hopes for these technologies in relation to environmental impacts as follows,

*'We've really messed up our ecosystems over the last 100 years. We've made a mess through deforestation. The hope would be that genetic technologies can reverse that and we can start to get the balance back for our ecosystems.'* (Norwich)

*'As a species we manipulate the ecosystem and the consequences of us doing that have been massive. Have we learnt from what we've done? Can we apply that learning to genetic technologies and make it right?'* (Norwich)

For others there was a strong perception that there were unforeseen consequences to the planet's ecosystems in using genetic technologies on plants or animals,

*'If you shift genes [in salmon] how do you know that's not going to mean they're going to die out within one generation because they can't adapt to the environment because you've changed that one gene?'* (Edinburgh)

with a particular concern about the consequences of cross-contamination between animals or plants that have undergone a genetic modification process and those that have not. It was felt in all locations that cross-contamination could lead to uncontrolled, negative consequences. For example, a genetically modified organism could escape its enclosure, breed with a non-GT organism and create a plant or animal that then decimates their environmental habitat.

As a participant in Edinburgh put it,

*'If there is an escape and the salmon get in to the system how would that affect the ecosystem and the environment?'* (Edinburgh)

Echoed by another who saw this as a point of no return for society,

*'I don't understand why they're trying to develop something that could have such horrendous repercussions if it goes wrong, and things do go wrong, whether through an escape, sabotage or whatever. As it says in one of these you can't put the genie back in the bottle. If you start contaminating the existing stocks that's it.'* (Edinburgh)

Discussions on farming techniques and the potential benefits in exploiting genetic technologies was seen as a hope for the future for some participants. Many of those involved in these discussions referred to the breeding of cattle and looked for solutions to some of the world's challenges in using genetic technologies in cows. One expressed a hope that genetic technologies could improve the immune systems of cows to address an over use of antibiotics in farming practices,

*'We pump antibiotics into the cows at an alarming rate whereas if we can modify them to have better immune systems on their own we wouldn't have to do that.'* (Edinburgh)

Another spoke of using genetic technologies in cows to provide a source of nutrition for human babies,

*'We were talking about cows possibly being modified to create milk more akin to breast milk and for that maybe to be used in countries where women are struggling to breastfeed, maybe in poorer countries.'* (Edinburgh)

For others genetic technologies could be used to address the factors contributing to climate change. They said,

*'An awful lot of the problems causing climate change relate to intensive farming and mass producing meats, for example the methane produced by cows. Is there some way that genetically modifying cows can alleviate the issues caused by that? So cows don't fart?'* (Edinburgh)

Some participants also felt that genetic technologies were not necessarily the solution to climate change. They felt that the solutions really come from re-thinking our food production systems in their entirety. This is picked up later in this chapter where we discuss genetic technologies as part of a package of solutions to global challenges (see section 2.7.2) but as one Edinburgh participant pointed out in this discussion on global challenges,

*'Our reliance on meat and land to farm the animals and we're clearing the Amazon in order to grow soya to feed to the animals, not their natural food. It seems a very bizarre system we're creating which isn't sustainable.'* (Edinburgh)

This was echoed by another participant who articulated strongly their desire to consider the challenge of the environmental impacts of our food production systems in a different way,

*'A lot of it seems to be looking for solutions to problems created by previous genetic technologies. Like dealing with the climate change caused by the massive intensive farming of GM crops and far too many cattle producing far too many gases as we're eating the wrong stuff. Trying to eliminate diseases in animals as they're kept in such overcrowded conditions. Breeding chickens without feathers so they take up less space and don't overheat in the spaces. I just feel we're attacking it from the wrong end. We should be looking at the root causes of all this rather than trying to put plasters on damage already done.'* (Edinburgh)

Population growth was an environmental challenge referred to in each location. One participant reflected on how genetic technologies can be used to address the challenge of feeding an expanding population,

*'[It's a real challenge to] work out how to feed an expanding population with limited resources, making crops more resistant, hardy to climate changes that are happening in certain areas. I know they can manipulate crops so they can withstand pests and droughts.'* (Norwich)

Participants reflected frequently on the possibility that genetic technologies, in providing treatments for previously incurable and life-limiting diseases could in turn contribute to another

global challenge that of an ever-increasing population. They felt that food security and sustainability to meet the increasing global demand for resources then becomes an even greater global challenge, which again genetic technologies might be called on to address. One participant summed it up as follows,

*'If you are talking about a technology that removed life-threatening diseases or disabilities then the issues around population growth, longevity of individuals, and sustainability of the world's population become issues along with the associated one of deforestation as we struggle to use our limited resources for an ever-expanding population.'* (London)

*'People are living longer than ever. In terms of environmental issues if people live longer, then that will have a massive impact on the environment'* (London)

They saw real consequences in improving the health and life chances of people through genetic technologies,

*'It's the consequences of fixing. You fix people so they live longer, but they need to eat more, they need more space'* (London)

and,

*'We should only live a certain amount of time. If we start messing up our genetic code what's the fallout from that? Are we then creating a problem where there is going to be more people living longer so we then need more food, we need bigger fish? Where does it stop?'* (Edinburgh)

But participants also saw that the growth in global populations was already an issue that needed solutions with or without the application of genetic technologies. These participants very much saw the use of genetic technologies in plants as part of the solution to this challenge,

*'In terms of population expansion and providing food I think I read somewhere there's a genetically modified crop that grows in very dry, hot conditions and is fairly easy to farm which for somewhere like Africa where there are poverty and food issues, especially due to the climate as well. That would be easier for them to self-sustain but also sell on.'* (Edinburgh)

## 2.4 Keeping people healthy

The most widely and strongly expressed hopes for genetic technologies discussed in the first workshops focused on reducing disease and suffering through treatments for humans as the two main ways in which participants framed their discussions. They thought about the significant challenge of reducing health costs in an increasingly over-stretched National Health Service and the need to reduce human suffering. For some participants one of the significant hopes for the future use of genetic technologies in operating faster and more cheaply could be,

*'Maybe reduced health costs. It could become a lot cheaper to treat people using the technology. You are not having to pay for other treatments. If somebody doesn't need a course of antibiotics for example.'* (London)

For others this was not only about treating disease and illness, but also about the reduction in NHS costs, or perhaps not needing a health service at all, inherent in preventing some or all illnesses and diseases,

*'If we're not getting these illnesses [in the future] because of the genetic technology the NHS won't be needed because we won't be ill. There's nothing for them to do. Only on an emergency level but not sickness and old age.'* (London)

For some this clearly ties in with the challenge of an ageing population. If people are living longer *in a state of health* the draw on the NHS will be much less in the elderly population. As one participant said,

*'If you can keep an aging population well for longer then they can be productive for longer. That sounds like they're slaves, but I'm trying to say people have a normal, fulfilling life and they can contribute to society throughout their life. You can then potentially free up costs around the health service, if people are better.'* (Norwich)

Others had specific technologies in mind that they had heard about in the media which they felt could help to reduce NHS and healthcare costs and a way of countering the costs charged by pharmaceutical companies. A Norwich participant said,

*'They've developed bananas, through genetic modification, to offer a vaccine against diseases such as cholera and hepatitis. They eat the banana, they get immunity to it rather than having to take drugs. It's good because it's a cheaper way to be able to provide drugs, rather than going to drug companies that charge a fortune.'* (Norwich)

This was taken up by another participant who hoped that genetic technologies could be used to develop cheaper drugs to treat cancers as they felt the inequalities in the current system were a significant societal challenge. They said,

*'I'm hoping you can use GM plants to make cancer drugs. This will decrease the price so it's available to all. Currently NICE develops a lovely new cancer drug and we can't afford it.'* (Norwich)

In all locations participants spoke of the need to reduce suffering and they considered that genetic technologies might well be a part of the solution. They highlighted benefits in treating disease and increasing food stocks in this context. As one London participant put it,

*'In theory genetic technologies reduce harm and suffering in the world if your baby isn't born from disease or Africa gets a good crop season. There surely are benefits to you which should be looked at and valued as well.'* (London)

For participants in Edinburgh genetically modified animals had a potentially very clear benefit in terms of zoonosis, the transmission of, for example, avian flu or tuberculosis, from animals to humans. They suggested,

*'You could genetically modify some animals to ensure that diseases that are currently spread from the animal to the human can be eliminated or reduced. There are all sorts of other benefits like that.'* (Edinburgh)

But they saw clear opportunities in using genetic technologies to reduce suffering in animals too. As one Edinburgh participant said,

*'We talked about benefits to humans of this and there are definitely genetic conditions that certain animals are predisposed to have. We can use this technology to help them.'* (Edinburgh)

Participants were very positive about this use of genetic technologies and the views of many are summed up in this quotation,

*'The overall impact on saving lives more generally [is positive], either through medicine or through genetically modifying animals in order to decrease the risk of disease being spread.'* (Edinburgh)

## 2.5 Keeping populations safe

It should be noted that this public dialogue on genetic technologies was conducted in the context of significant terrorist attacks in England in March, May and June 2017; increases in nuclear testing by North Korea and relations between Russia and the UK being at their, 'most strained point since the end of the Cold war<sup>5</sup>.' All of which was extensively reported and commented on during the dialogue delivery period. Understandably therefore discussions turned to enquiries as to the potential for genetic technologies to do harm rather than good if used in terrorism, warfare or as a threat of war. People thought of this in general terms, as in this comment,

*'It could get into the wrong hands. With terrorism and war there's nothing to stop someone using it for the adverse effect.'* (London)

And in terms of more specific modifications, to create a virus for example. As participants in London and Edinburgh said,

*'They could create viruses as well... There is always this risk that you might think, 'Oh, somebody else is developing a weapon. We don't want to go into a war but we have to have an advantage in case we get attacked. So we need to also develop that [virus] technology.'* (London)

*'I'm thinking of the technology being used in a bad way. You could spread disease. The technology used to eradicate the gene that carries disease could be put back into something in a negative way.'* (Edinburgh)

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<sup>5</sup> House of Commons Foreign Affairs Committee [The United Kingdom's Relations with Russia](#), 7<sup>th</sup> report of session 2016-2017, House of Commons, February 2017



They also saw that genetic technologies might have the potential to do harm in more subtle ways by poisoning water, or destroying food or other means of life. In Norwich a participant mentioned their fear that,

*'You could release a toxin into the crops that kills all the food. That's a way to cripple a country. Countries where war effects whether people will be fed or not fed.'* (Norwich)

And in Edinburgh they spoke overtly of the fear that genetic technologies could be used as a weapon,

*'If it can be used as a weapon? If we're doing it and we're very good at keeping an eye out and making sure it's ethical can North Koreans or someone like that get into this and then pollute our systems and use it as a weapon?'* (Edinburgh)

For some this was a very far off threat until they read around the subject before coming to the dialogue. One participant said,

*'When I was researching genetic technologies before coming here there was a statement made by the United States Director of National Intelligence who named genome editing as a potential weapon of mass destruction. There's a big piece about it and that hadn't occurred to me at all.'* (Edinburgh)

## 2.6 Underpinning principle: improved communications

Underpinning all the hopes expressed in these initial discussions on genetic technologies in relation to global challenges was the belief that for genetic technology to gain trust amongst people in the UK, there needed to be far more public discussion, education and considered media coverage of how genetic technologies are developing, who is working on their development – both private companies and academia and who is regulating them and how. As a participant in London put it,

*'Where's this country going to be [on genetic technologies]? We don't know and it's for the scientists to try and educate us enough to make a sensible decision.'* (London)

As participants observed themselves during discussions, a consequence of their lack of knowledge was that often more fears than hopes were raised. A fear underlying much of what participants expressed was a general fear of change and new developments which would be applicable to any new and as yet untapped development in society. This participant sums up the views of many,

*'Everybody gets old and most people get ill, all people die. That's the way it's always been. If they can start changing that where we don't get ill and we don't die so young, it's a different world.'* (London)

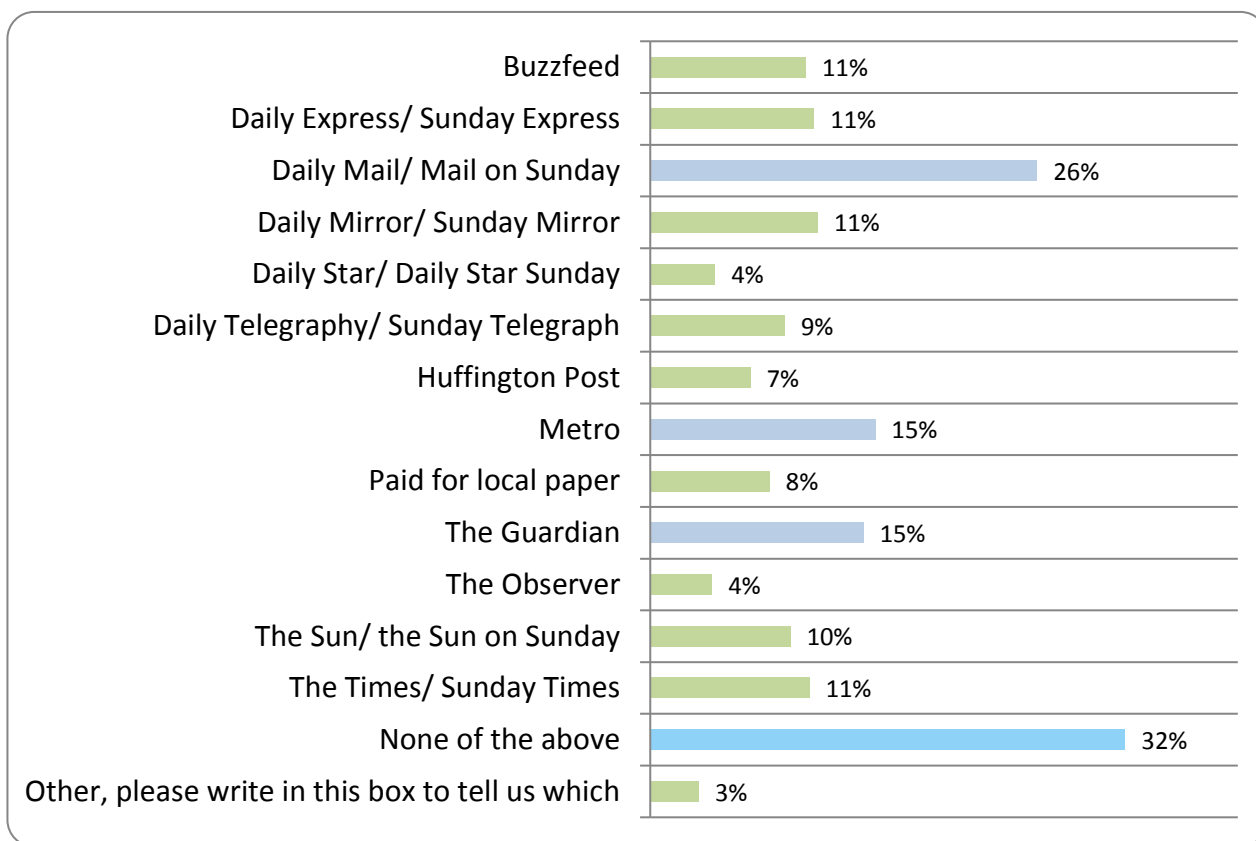
Participants were also aware that their initial views on genetic technologies could have been informed by the media they consume. A group in Edinburgh reflected on this by saying,

*'I guess what we talked about firstly was that we didn't have a great deal of understanding of genetics or the work going on, but we were struck by how quickly we moved to the difficult questions about it. Should we be doing this? A lot of our impressions may be coloured or distorted by media responses.'* (Edinburgh)

We did not ask in the recruitment processes for the dialogue what potential participants' media preferences were, but this was asked in the survey where we saw the largest group of respondents (32%) not consuming any information from the media outlets listed (see figure 9) with the next popular outlets being the Daily Mail/ Mail on Sunday (26%), Metro (15%) and The Guardian (15%).







Survey respondents were also asked about their social media preferences with by far the majority using Facebook (66%), followed by YouTube (40%) and Instagram (26%).

Figure 9: Which of the following media outlets, if any, do you read regularly either in print or digital format? By regularly we mean at least three times a week.



## 2.7 Views tempered by hopes and fears

The recognition by participants that their views initially were drawn from their media consumption, their own life experiences and their common sense is important. It allows for change through the dialogue process and for initial hopes and fears to be recognised and then further explored in a fuller discussion informed by the evidence provided in presentations, case studies, the timeline, jargon buster and through ongoing interaction with those who have professional knowledge and experience of the issues. Nevertheless these early views are significant as they recognise the hopes and fears people bring to the dialogue process and they are summarised in figure 10.

Hopes	ALL APPLICATIONS	Fears
<p><b>A more equitable society: with better access to health care, food and energy</b></p>		<p><b>Only available to the wealthy = a more divided society</b></p>
<p><b>Progressing our scientific knowledge</b></p>		<p><b>Cuts in other fields of scientific research</b></p>
<p><b>More education, outreach and public conversations about genetic technology</b></p>		<p><b>Problems are covered up, speed of development leaves public behind and not explained</b></p>
<p><b>Profit sharing/mix of public and private funding: transparency to ensure social as well as corporate benefit</b></p>		<p><b>Genetic Technology research and development is driven by greed for profit and not by social good</b></p>
<p><b>Regulation to protect against monopolies and greed driven developments and ensure transparency</b></p>		<p><b>Lack of regulation or regulation that is too close to the corporations</b></p>
<p><b>Help to adapt to or reverse climate change</b></p>		<p><b>Cross contamination and mutation = unknown impact on eco system</b></p>








HUMAN		
Reduce disease and suffering e.g. cure cancer		Use for enhancement and the quest for perfection
Live longer, healthier lives		Population explosion
Healthier population that is more economically active		People used as guinea pigs, weapons or manufacturing units
Job creation in a new field of technology		Job losses e.g. farmers squeezed out by large producers
PLANTS		
More food available to more of the world's population that is nutritious and affordable		Greater share of food production owned by big corporations or profit and not social good
ANIMALS		
Avoid or reverse extinction of species		Editing out deliberately or as an unintended consequence: people, plants and animals
Improved animal welfare		Animals exploited as manufactured products

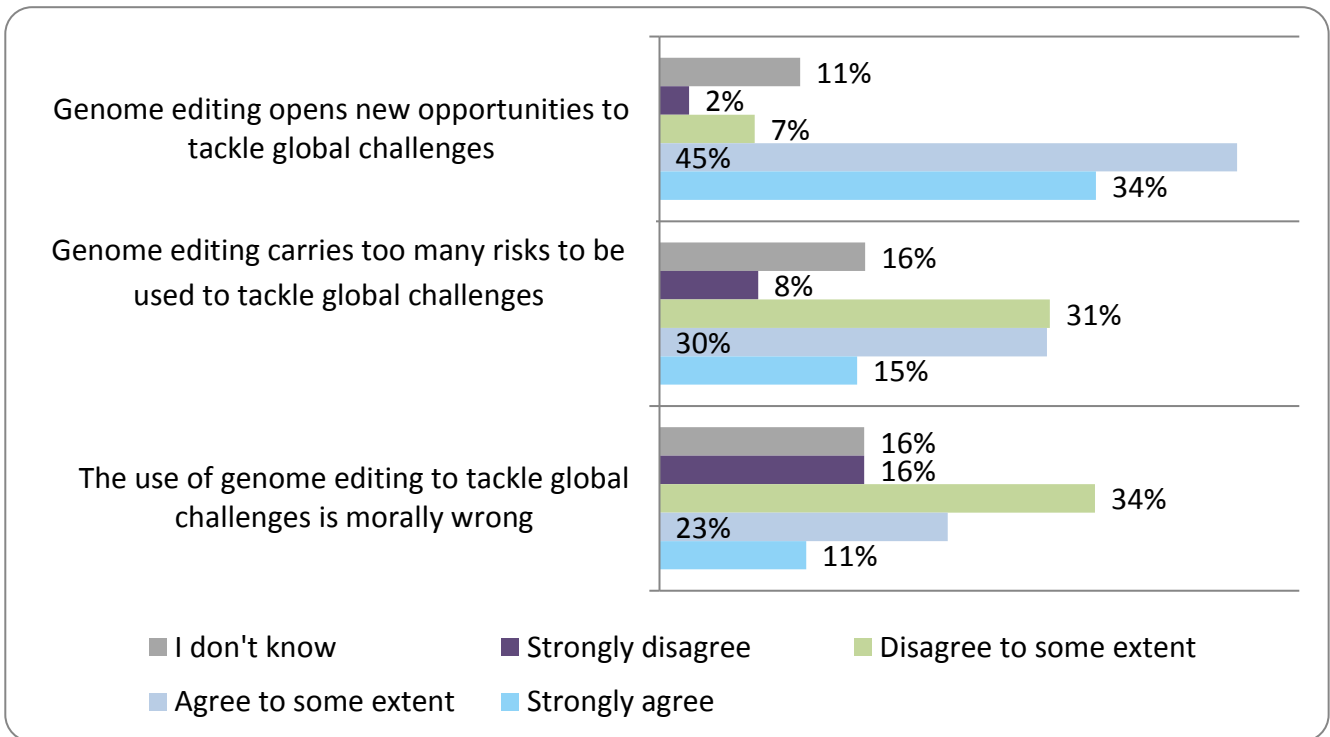
Figure 10: A summary of the hopes and fears raised by participants in the early part of round 1

The survey findings around genetic technologies being used to tackle global challenges (figure 11) demonstrate three main points, that:

- Respondents' views on genetic technologies are tempered by their hopes and fears
- This is a complex area where the answers are not clear cut. For example 45% of the respondents 'agree to some extent' with the statement that genome editing opens up new opportunities to tackle global challenges and 34% 'strongly agree' (79% in total). This predominantly positive response to the opportunities offered by genetic technologies is reflected in the responses to the statement that the use of genome editing to tackle global challenges is morally wrong: 16% 'strongly disagree' and 34% 'disagree to some extent' (50% in total). However, the statement 'genome editing carries too many risks to be used to tackle global challenges' showed that a majority of respondents are wary of potential risks: 15% 'strongly agree' with this statement, 30% 'agree to some extent' (46% in total), with 31% of respondents 'disagree to some extent' and 8% 'strongly disagree' (38% in total).

- There is a need for more understanding of genetic technologies in the wider population so that society can consider the risks and moral issues that arise from their use to tackle global challenges, for example more people tend to respond, 'I don't know' to these statements than we see elsewhere in the survey.

Figure 11: Responses to statements on genome editing being used to tackle global challenges



## 2.8 Genetic technologies as part of a package of solutions

In reviewing the global challenges participants brought to the discussion, reflecting on the hopes and fears for genetic technologies raised in the initial stages of round 1, and drawing on the survey findings we find that the UK public is cautiously in agreement with the idea that genetic technologies should be used as one of the ways of addressing global challenges. As set out in figure 12, in the survey the majority of respondents (62%) either 'strongly agree' (24%) or 'agree to some extent' (38%) with this if there is no other way of achieving the same ends. Likewise, the majority (58%)<sup>6</sup> either 'strongly agree' (18%) or 'agree to some extent' (41%) that genetic technologies should be used as one of the way of addressing global challenges if it can provide a lower cost option; and a majority (65%) 'strongly agree' (27%) or 'agree to some extent' (37%) that genetic technologies should be used if they are a less environmentally harmful option than the alternative solutions available to society currently.

In figure 13 a similar pattern continues with a majority of respondents (60%) 'strongly agree' (25%) or 'agree to some extent' (36%) with the idea that genetic technologies should be used as one of the ways of addressing global challenges if those technologies have fewer negative side effects than existing alternatives; 46% if they are subject to fewer patents than other options for achieving the same outcomes (15% strongly agreed; 32% agreed to some extent); and 48% if the technologies

<sup>6</sup> Where stats do not sum exactly this is due to rounding errors.

provide a more profitable option than existing alternatives (14% agreed strongly; 33% agreed to some extent). It is here that the survey results differ somewhat from the dialogue findings. As we have seen there was little appetite amongst dialogue participants for genetic technologies to be used for profit as this was seen as counter to the wider public good and was perceived as potentially a risk for society, re-enforcing inequalities in terms of those who could afford to take advantage of the benefits genetic technologies might offer society and those who could not.

A majority (70%) of survey respondents either strongly agreed (41%) or agreed to some extent (30%) that each use of genetic technologies should be subject to careful scrutiny and regulation. This survey finding chimes very closely with the findings explored in section 4 of this report where the majority of participants were strongly in favour of rigorous regulation of genetic technologies as the framing for their acceptance of developing UK research into genetic technologies.

Figure 12: Genetic technologies should be used as one of the ways of addressing pressing global challenges if:

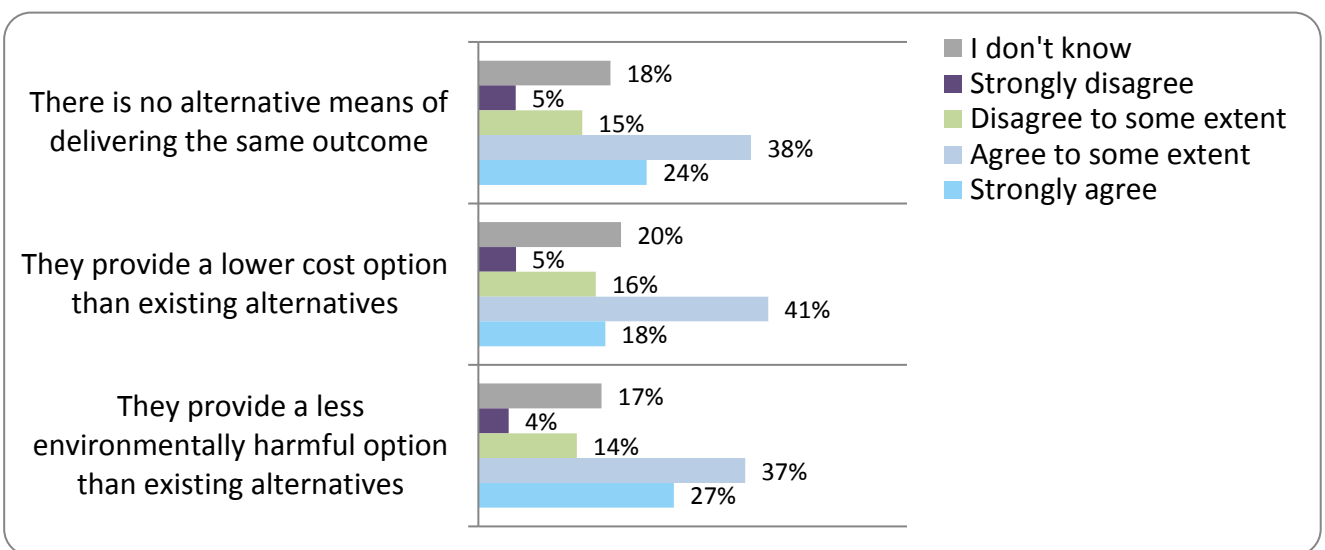


Figure 13: Genetic technologies should be used as one of the ways of addressing global challenges if:

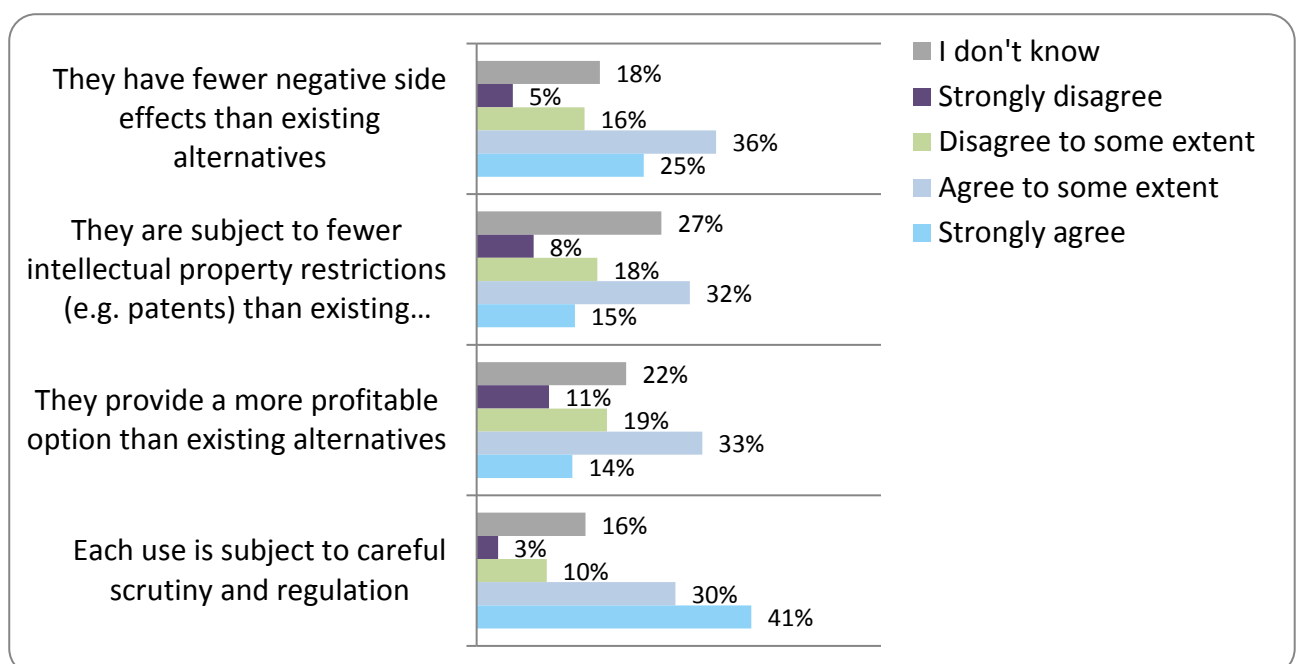
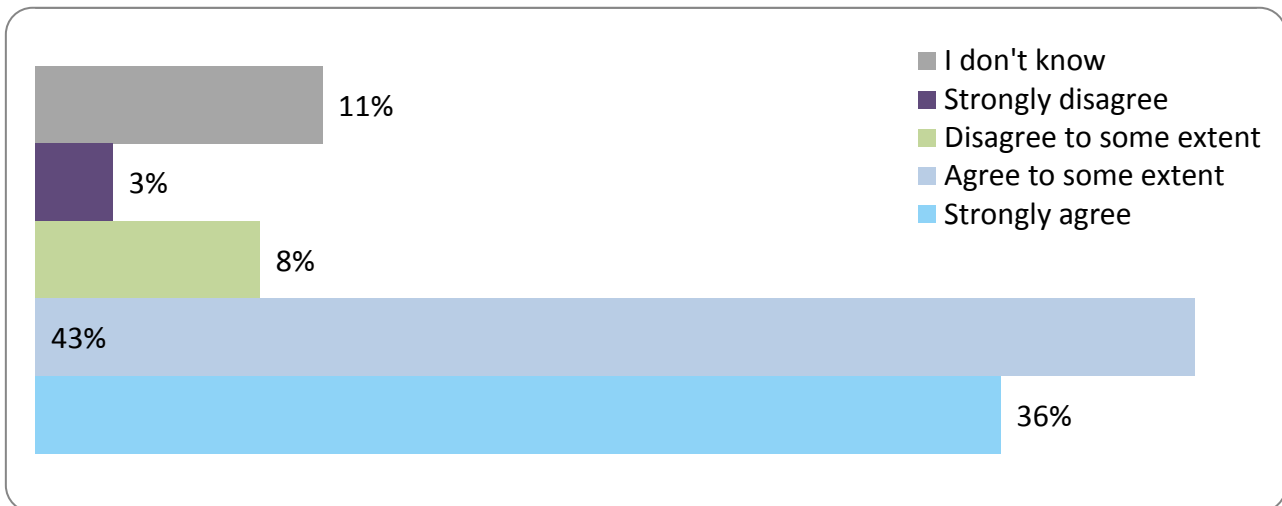


Figure 14: The use of genome editing must be balanced with other ways of tackling global challenges



Participants in all locations in the dialogue made a range of suggestions for how genetic technologies might form one part of a range of solutions to address global challenges. This was strongly supported by the survey findings (see figure 14) where 36% of respondents strongly agreed with the statement, 'The use of genome editing must be balanced with other ways of tackling global challenges' and 43% stating that they tend to agree with it (78% in total).

Dialogue participants in London, looking at genetic technologies in relation to humans, considered a number of alternatives. One of the challenges they found quite testing was considering whether or not genetic technologies should be used to treat diseases which are already managed well through existing medication. One participant spoke about asthma for example,

*If you have an inhaler for asthma and you can manage, which I do, of if my parents had had the choice, 'There is a good chance he's going to have asthma, but we can sort that out.' It's a strange one to solve.'* (London)

They were unsure whether or not using genome editing to solve a treatable condition such as asthma would be an appropriate use of the technology.

For some the alternative solution to genome editing to correct a genetic mutation in human embryos was clear cut,

*'Choosing to adopt would bring an even greater benefit for society. Less children growing up without parents.'* (London)

Others could see that not all alternative solutions are appropriate for every circumstance,

*'One of the alternatives is parents can choose to adopt or have gamete or embryo donations with a loss of direct genetic connection to their child. That may not be applicable to all people because they feel they need to have direct connection to their child to make them a parent.'* (London)

A number of the expert witnesses in the process commented that many of the points being made in relation to genetic technologies, including people's hopes and fears for them, could be applied to

a discussion on any subject involving new and developing technologies. Participants were aware of this and reminded of it by the facilitators but they also pointed out where they saw differences,

*'There's a difference in the technology from genetics to IT technology, where we're in a regulated environment with genetically modified drugs and crops, whereas technology isn't regulated, so that can grow exponentially and go all over the place.'* (Norwich)

Others saw technology as one of the alternatives that could be used to address global challenges. They referred to robots, nanobots, artificial intelligence and computer coding all working to solve various global challenges.

### *2.8.1 Behaviour change*

Participants in all locations also spoke of the importance of food, nutrition, health and the environment as alternative solutions to employing genetic technologies. They spoke of education on nutrition and healthy living as an important alternative to using genetic technologies to treat preventable disease. There was a sense that large numbers of people do not understand how to live and eat healthily and if they did there would be fewer diseases to treat. As one participant put it,

*'I know how to be healthy. I know the balance of protein, carb and fat, but most people have no idea.'* (Norwich)

For others there is a much bigger picture to be considered particularly in combatting the environmental impacts of society's choices. A participant in Edinburgh referred to the increasing amount of plastic in the worlds seas,

*'There are huge consequences for all of these things we throw away. It's how we dispose of things so we're not polluting. Even if you genetically modify fish, if plastics constantly return to their stomachs they will still go out and get polluted again and we've got the same problems. You need to think about how you impact on their lifecycle and how that impacts back on you.'* (Edinburgh)

They were also very concerned with food waste, and talked about genetic technologies prolonging the shelf life of food but felt a better alternative solution would be to create behaviour change to ensure the better management of food waste. A participant in Edinburgh said,

*'What about legislation on food waste? To create bigger fish with the amount of food waste in the UK seems strange. People could be fined for wasting food.'* (Edinburgh)

In relation to the salmon case study worked on in Edinburgh participants also spoke about the importance of behaviour change as a way of tackling the global challenge of reducing the negative ecological effects of fish farms,

*'Should we focus on changing to other fish? Can you change consumer behaviour through this process and provide alternatives? They are trying to help because salmon is in high demand but maybe tilapia would be better to focus on and mass market that.'* (Edinburgh)

A clear alternative to genetic modification of salmon was discussed by one group in Edinburgh. They spoke of the need to encourage people to replace the meat in their diet, particularly cheaper cuts of meat, with other dietary protein. One participant spoke of the need for a significant change in consumer behaviour,



*'We need to face our responsibilities as consumers. We can talk about cruelty to animals but if I go and buy pork chops for £2.00 at Iceland I'm going to be getting cheaper meat, but that has to come from a farm and very cruel conditions...I hear a lot of people going for other protein sources, to insects for example.'* (Edinburgh)

### 2.8.2 One choice amongst many

It was felt by many that the range of solutions available was as wide as the range of challenges for which solutions are being sought,

*'Almost everything. Investment in public health, research in every other type of drugs and therapy.'* (Norwich)

People suggested that genetic technologies are another set of tools amongst many including selective breeding,

*'If you cross two things together you don't know what's going to happen. You're trying to get a specific trait but you could get ten different ones that you didn't want. If you're doing gene editing you're getting only that very specific thing that you want. It's like someone creating a drill to drive in screws instead of a screwdriver. It's just a different technique.'* (Edinburgh)

Participants felt that genetic technologies should be reviewed alongside other options and a benefit analysis conducted to ensure that society,

*'Prioritises the most ethically beneficial option, for example by rationing fish stocks.'* (Edinburgh)

People were concerned that research into genetic technologies might be diverting funding and attention away from other areas of research. In relation to the Atlantic salmon case study used in round 1 in Edinburgh one participant said,

*'How much public funding went into that research to get a fish after 25 years? That could be saving people [by researching] cures for malaria and cancer treatments.'* (Edinburgh)

In this early stage of the dialogue people wanted to understand why genetic technologies should be prioritised over other forms of research in to treatments for disease for example,

*'How can governments and donors to this research justify giving money to this over something else that can also be influential and life-changing? What makes this so special and how can we know that?'* (Edinburgh)

Participants also recognised how long humans have been adapting species and in a sense saw this as an indication that genetic technologies have always been in the suite of options available to humanity. As one Edinburgh participant put it,

*'That's every product that's been farmed, every fruit or vegetable in existence has been selected for a particular reason because it tastes good or it grows better. Is this not just a more refined and accurate version of what's been going on for thousands of years?'* (Edinburgh)

# 3. Frames and contexts that moderate acceptability

## Chapter 3 summary

In this chapter we explore the frames and contexts that moderate public acceptability of developing UK research into genetic technologies. The findings are drawn from participants' discussions about the case studies in the dialogue sessions and specific comments made during the roving ideas storm in round 2 on what is acceptable and unacceptable for society using the following frames:



Cost



Individual Welfare



Collective Welfare



Environment



Regulation

An analysis is given of the views that are common to the use of genetic technologies in humans, plants and animals. The acceptance of which are summarised as those applications which:

- Promote equitable access to genetic technologies as they are developed
- Prioritise collective welfare
- Enable the science to develop further and knowledge of future applications be extended
- Provide cheaper health interventions
- Prioritise positive and reduce negative environmental impacts
- Have benefits that outweigh risks to human health, animal welfare and the environment
- Alleviate suffering
- Use transparent processes.

And applications which are unacceptable as being those which:

- Edit out difference and create a monoculture
- Prioritise individual and/ or corporate wealth
- Drain currently over-stretched NHS resources
- Enable humans, plants or animals to be weaponised
- Are introduced with insufficient safety monitoring or measures
- Restrict freedom to choose whether they should be applied or not
- Reduce biodiversity or harm the ecosystem and related food chains
- Contaminate plants or animals not grown or reared using genetic technologies
- Are not sufficiently regulated, or equally are so over regulated as to stifle scientific discoveries.

The survey findings picked up on in this chapter demonstrate that respondents are broadly in agreement with dialogue participants on the frames and contexts that moderate acceptability. The chapter therefore gives a detailed analysis of the commonalities and differences in attitudes and views depending on the application grouped into the five frames listed above, beginning with cost.

In this chapter we speak of the difference in findings depending on age as we find older segments are more in favour of stricter control of genetic technologies than those who are younger in the population.

## 3.1 Cost

Participants considered a range of factors for what they felt was acceptable for society in terms of the cost of genetic technologies.

**Acceptable: Available to and affordable for all**

From early on in the dialogue participants commented on the need to ensure that genetic technologies should not widen divisions in one society or country by improving the lives of some whilst leaving others behind,

*‘One of my hopes was that it affects society positively, that’s quite broad but when I say that I mean it doesn’t lead to a divide, ethical or economical.’ (London)*

Across groups and locations, participants felt strongly that genetic technologies should help to bring greater equity to the world, for example by making nutritious food more available in developing countries and that medical treatments should not just be for those who can afford them,

*‘The cost would be acceptable as well if it was affordable for everybody not just the super-rich’ (Edinburgh)*

Although the general view was that resources should be spent primarily on applications that benefit more people, consideration was given to the fact that single case applications should not automatically be ruled out as they may offer opportunities for science to progress. In the context of the Baby Layla case study for example (see appendix 7), where non-heritable genome editing for medical treatments was tested, a group of participants discussed that,

*‘There may be a wider public benefit from trying something first, we’ve got to bear that in mind too.’ (London)*

**Acceptable: Profits leading to innovation and contributing to taxes**

The ethics and implications of making profit from genetic technologies was widely discussed and debated by participants. Whilst there was a strong sense from many that a technology developed solely for profit would be bad for society, there was also an understanding that profits made by organisations could be used to fund further innovation and would also contribute to UK tax revenue which would be of benefit to the economy. As a participant in Edinburgh said,

*‘I guess if it’s taxed you could have the redistribution of money that could therefore collectively benefit society.’ (Edinburgh)*

One participant referred to a collaboration between pharmaceutical companies and the World Health Organisation that he thought could be a model for genetic technologies,

*‘If it is one of these medicines that’s considered crucial, a pharmaceutical company, before they sell it to the wider public, have to give a certain amount to the World Health Organisation (WHO) who then give it out at a reduced cost, or free, to places that really need it. So that kind of scheme does*

*exist for a few things where companies, before they can sell it for their own profit, have to give a certain amount to the WHO.'* (Edinburgh)

Acceptable: Costs more but good outcome for the environment

If a genetic technology is more expensive than other interventions, but could prove to be beneficial to the environment, then many participants saw this as a reasonable justification,

*'Ethical costs should be taken into consideration as well, shouldn't they? So if it costs a bit more but it's better for the environment, surely we should do it?'* (Norwich)

Acceptable: Use genetic screening to help predict healthcare costs

The idea of using genetic screening to help the UK to predict healthcare costs and plan healthcare provision was raised as a positive prospect by one group,

*'If you were able to do genetic testing early on, you might also become more efficient as a government body, and say you notice that for some reason there seems to be a huge amount of people with this condition, what are the common factors, they might be able to predict the causes.'* (London)

This should include all costs, not just the cost of the test,

*'It's not just the cost of the test, it's the cost of the person to interpret it, any longer term therapies or treatments. It's not a one-off payment is it? It's going to have financial implications, it's somebody's journey.'* (London)

Acceptable: Cheaper health interventions

NICE's guidelines on drugs that should or should not be available on the NHS were often referred to by participants discussing the affordability of treatments. There was some hope that genetic technologies could lead to cheaper health interventions that were less likely to be ruled out by NICE's cost guidelines, meaning fewer instances when people would have to find the funds themselves or do without treatments such as life prolonging cancer drugs.

This view was echoed in the survey where respondents were asked to give their view on the statement, 'genetic technologies should be used as one of the ways of addressing pressing global challenges if they provide a lower cost option than existing alternatives'. As we have seen (figure 12) this is a statement to which the majority (58%) either strongly agreed (18%) or agreed to some extent (41%). Only 5% of the sample strongly disagreed with the statement with 20% saying that they didn't know how they felt about it.

Acceptable: Investment in proportion to the outcome and for future gains

Whilst most participants understood that developing any technology can be costly and the outcomes uncertain, there were mixed views on the acceptability of investment, particularly of public money. Some wanted the investment to be justified by the likely outcomes, whilst others were more accepting of the uncertainty of research and that more rather than less investment is necessary to yield successful, widely beneficial technologies in the future,

*'If it costs a bit more now but works out cheaper in the long run, because it could take more to actually set up but overall long term running costs could be less. So it's good to work out the whole picture.'* (Norwich)

**Acceptable:** Continue to invest in other solutions unless genetic technologies are the only option  
In line with the discussions about the role of genetic technologies in addressing global challenges (see section 2.8.2) dialogue participants shared the view that investment in genetic technology is acceptable as long as other interventions are also funded. Participants continued to feel uncomfortable with the prospect of allocating funds only to genetic technologies. As someone in Norwich said with regards to plant applications,

*'Genetic technologies are good but not sufficient to solving food supply issues. We should be taking a broad perspective talking about different food supply methods with genetic technologies as one of them.'* (Norwich)

The exception to this was when a genetic technology was determined to be the only solution, such as in preventing extinction of a species,

*'I think what would be acceptable to me is if it turns out that the GM solution is the only solution not the best or the cheapest or whatever, but the only solution then whatever cost is going to be acceptable.'* (Edinburgh)

As previously noted (see figure 12) we find in the survey broad agreement with this comment with 38% agreeing to some extent that, 'genetic technologies should be used as one of the ways of addressing pressing global challenges if there is no alternative means of delivering the same outcome' and 24% strongly agreeing (62% in total).

#### **Unacceptable: A motive of pure monetary gain**

Deep suspicion was generated when participants discussed the topic of profiting from genetic technologies. Many participants saw the profit motive and social good as diametrically opposed. There was a belief that when conducting experiments with new uses of genome editing or genetic modification, profit should not be the most important influencing factor. There was fear that a technology that is developed purely for profit would lead to wider divisions in society as it would only be available to those who could afford it and further reduce the living standards of those who could not: be it technology for human health, food or energy sources.

We find that respondents to the survey reacted somewhat differently to the statement, 'genetic technologies should be used as one of the ways of addressing pressing global challenges if they provide a more profitable option than existing alternatives.' Figure 13, shown previously, shows that 33% of respondents agreed to some extent with this statement and 14% strongly agreed with it. Dialogue participants, who had been presented with more evidence and information on uses for genetic technologies felt more strongly than the survey respondents that a purely profit motive was not acceptable.

### Unacceptable: Taking money from current health services

Many participants said that they did not want to see funding for genetic research coming from the budgets of current services, most particularly the NHS. Ideally, they want to see an entirely separate funding stream for publicly funded genetic research or funding shifted from budgets such as military spending on Trident,

*'It's unacceptable if the costs are in detriment to other services that are already exist like hospital and the hospitals start suffering because their budgets are tight enough. If we start taking away money from them because we're playing around with genetics.'* (Edinburgh)

With recognition of the opportunities for future savings one of the groups in London said they would prefer to see a budget ring-fenced for genetic testing,

*'I think that the NHS has got significant funding problems anyway, so pulling funding for genetic technology from the current NHS budget is wrong. The government should ring fence another budget for this kind of work to make sure the NHS isn't put under pressure.'* (London)

*'Because if it does work, in the long term, the NHS will save.'* (London)

### Unacceptable: Publicly funded technology exploited for private profit

The precedent of Public Private Partnerships, where publically owned assets such as hospitals are sold to and leased back from private companies was seen as a worrying path for publically funded genetic technology to follow. As a participant in Edinburgh said,

*'If the government were to then say, 'Ok we're going to give the rights out for companies to do these', only for them to make incredible amounts back, would that be a socially acceptable cost to us in terms of having to pay large amounts of funds back? For some people it doesn't matter, sometimes it does, but arguably some have driven the hospitals and the schools and things to be built but at what long term effect, so clarity I think in terms of the cost.'* (Edinburgh)

### Unacceptable: Creation of monopolies

Case studies including the AquaBounty salmon example, prompted some participants to raise the prospect of companies who own a genetic technology using it to flood the market with a cheaper product, kill off competition, particularly with local farmers and then raise prices when they have market dominance. This fear was exacerbated by the idea that the methods of cultivating the previous, non-genetically modified crops or animal products could be lost over time and mean that people would not have the choice to revert back,

*'Who owns this technology, is somebody getting very, very rich in Canada? And does it put everybody else out of business or do they pass on that, so the existing farmers become able, you know, to develop GM salmon?'* (Edinburgh)

## 3.2 Collective welfare



Acceptable: Positive impact for large cross section of world population

There was a strong view amongst participants that it's important that genetic technologies should be used to solve an issue that enhances society and do no harm to human health, animal welfare or the environment.

As participants in London put it in their first discussions,

*'Today, in the papers, it's all about designer babies, embryos. Why are we even talking about that? Why don't you sort out some common problem to our society first, and apply this amazing technology to something that's beneficial to everyone?'* (London)

It was important to participants that genetic technology is applied first of all to something that affects a large cross-section of the world population,

*'Maybe we choose a problem that affects the whole world, not just one country, or a small group of people.'* (London)

Acceptable: More equality in the world

Participants saw the opportunity for genetic technologies across all applications to help create a more equal society, where there would be less suffering through illness and more resources such as food and energy available to developing countries,

*'For me the strongest is if we help to remove inequality, because if you're born with a genetic disease, you can't do anything about it. I think if there's a shift to empower people I think that's a benefit. Because it's unequal now.'* (London)

An important factor in genetic technologies helping to create a more equal society was the development of partnerships between western and developing countries. Participants thought it important that sharing the knowledge around genetic technologies would avoid smaller, less well-off countries from being 'test-beds' without having the chance to learn and apply the benefits of the technologies for themselves. Participants talked about working across national boundaries,

*'So for instance, organisations like the UN, they should have a budget to allow this to be taking place in third world countries.'* (Edinburgh)

*'The western world ... it's in their interest, and also in the worldwide collective interest to basically provide some funding so that research can carry on in third world countries, so they have access to it as well.'* (Edinburgh)

Acceptable: Long term view of benefits

The idea that the benefits of genetic technologies may take many years to be realised was recognised by some participants. As participants in Norwich said,

*'I think you'd need to think about the future of us, the planet, as a collective. If you're talking about collective welfare that seems to indicate living beings, like animals and humans here and now, but what about the future? So if [...] it brings benefits in the future, not necessarily now, to end suffering [...] for our next generations it's like the step on a long list.'* (Norwich)

*'It's taking a long-term view isn't it, rather than short-term product view.'* (Norwich)

Some could look ahead and see future generations being amazed at how conservative we were in our views on the potential of genetic technologies,

*'It's unacceptable for us to think of our short term welfare collectively instead of future generations who are yet to come. Who's to say they might scoff at us for turning our nose up at technological advances.'* (Edinburgh)

Acceptable: Recognition that our choices will evolve

In some conversations about what is and what is not acceptable, participants recognised that attitudes held today will very probably evolve as evidence comes forward and society adapts. This is illustrated in a discussion amongst participants in London,

*'Some of the things that we're saying today may be more acceptable in the future. Our mind-set changes. Especially as people can put a lot more faith in the technology and it becomes proven, and there are more options, it becomes easier to believe in it.'* (London)

Acceptable: Greater understanding of conditions

An acceptable dimension to developing genetic technologies for some participants was that it would help society better understand the root causes of a disease or a condition and that this greater understanding could lead to more tolerance. Participants gave examples of how people who had seizures used to be thought of as insane until their condition, e.g. epilepsy, was understood.

Acceptable: Consideration for religion and belief

Across the applications participants made reference to the importance of wider consultation amongst faith groups prior to making genetic technologies more widely available. As a participant in the human application dialogue said,

*'I'm a Christian, and the way I was thinking about it is that everyone is made in God's image, and the fact that the Christian community now starts saying that if you're changing all of this, you're messing with God's work. [...] A lot of these leaders may be thinking this is wrong and start preaching it to their congregation, and it may flip on its head, where you tried to do good but now you have people thinking that it's bad and trying to tell other people that.'* (London)

Unacceptable: Reduced diversity

Editing out certain conditions in humans made some participants uncomfortable, leading them to ask who defines what a disease and disability is and whether removing it from the world would lead to a monoculture and a resultant less empathetic and tolerant society,



*'It would worry me because the consequence of screening could be either editing a whole group of people out, or potentially killing them off.'* (London)

For a few participants, a society where disability and disease has been significantly reduced could result in people losing their ability to be compassionate. This stemmed from a sense that an important 21<sup>st</sup> century human quality is our instinct to care for and accommodate people with different abilities,

*'If we talk about embryo treatments, you'll then have a generation of people who have grown up never having to face any difficulty. That lack of challenging environments, I think it's unacceptable. You're going to have a generation of people who have never had to accommodate or, never had to think about anything, any tragedy or tragic situation, what will that do for society? It may make people less compassionate.'* (London)

Unacceptable: People used as guinea pigs, weapons or manufacturing units

Fears of a dystopian future where humans or animals are genetically modified for specific uses, such as to test emerging technologies, to be efficient 'machines' or to be designed as weapons illustrate people's fears of how genetic technologies could be taken far beyond their current form into areas that would cause us to question what it means to be human,

*'Everything costs us money though. If this would help us so we didn't need to sleep, we didn't need to eat, all of this, then it would take away quality of life. We'd just be becoming like machines.'* (London)

*'I think it would be unacceptable if we totally conceptualised that in terms of productivity. I think as far as retraining and multi specialising goes, it's beneficial to yourself, and socially, it's great, but just because that's not the way the world works, you're more valuable if we can get more work out of you. I think that would be a negative.'* (London)

Unacceptable: Insufficient safety measures

Throughout the discussions in all locations participants shared the view that safety of the technology is very important, as someone in one of the groups in Edinburgh summarised it,

*'Safety in terms of human health, the food chain and the eco system.'* (Edinburgh)

This was often linked to concerns about the safety of research,

*'So it doesn't get out of the lab before it is fully tested and deemed safe.'* (Edinburgh)

and potential impacts on the food chain and human or animal health of applying genetic technologies or eating genetically modified plants. As someone in Edinburgh said about genetically modified fish farmed salmon,

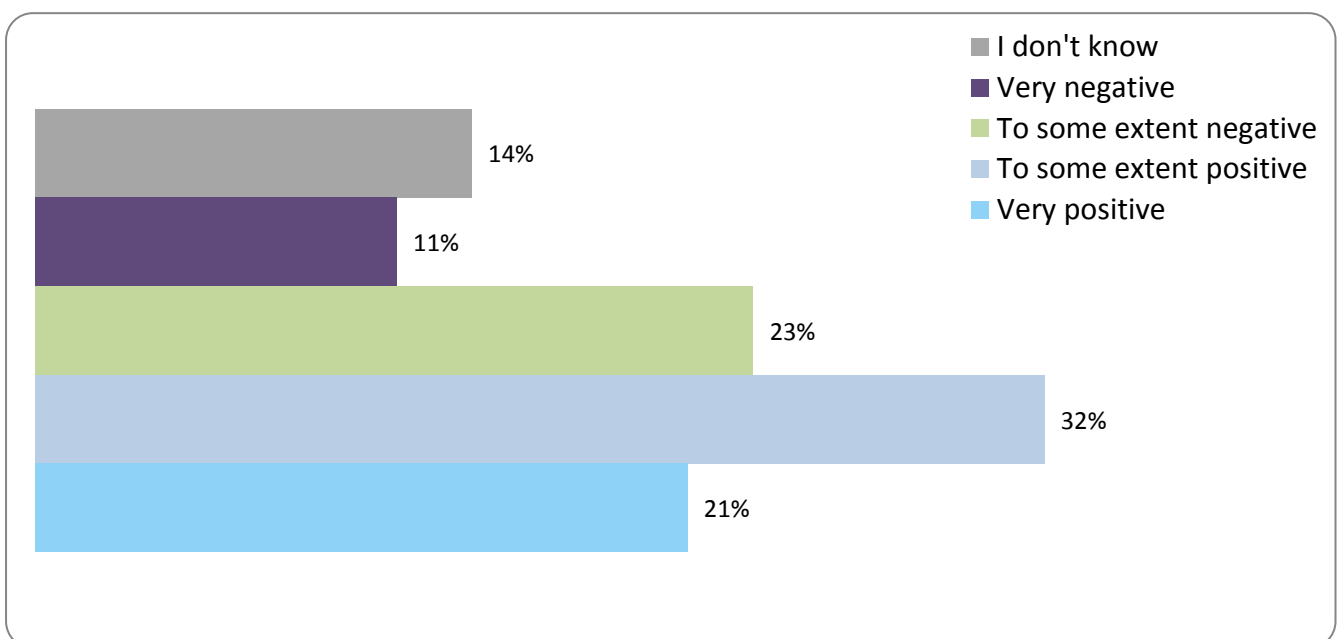
*'If you had salmon swimming in the Atlantic and fish-farmed salmon, how would they look? What would they be fed? How would it be different? How would it affect them?'* (Edinburgh)

And a participant in Norwich,

*'Animals eating the plants unknowingly, would they experience the effects of the modification in question? What are the risks if that was to happen? Will it kill off invertebrates? Will it make people or animals sick?'* (Norwich)

Overall there was a view across the applications that the benefits of using genetic technologies have to very clearly outweigh the risks to human health, the environment and animal welfare. All these points were tested in the survey. For example respondents were asked to state the extent to which they agreed with the statement, 'genetic technologies should be used as one of the ways of addressing pressing global challenges if they have fewer negative side effects than existing alternatives'. 36% of respondents agreed to some extent and 25% strongly agreed with this statement (60% in total. See figure 13, shown previously). The survey also asked people to respond with their view on whether genetic technologies should be used as one of the ways of addressing pressing global challenges if they provide a less environmentally harmful option than existing alternatives, to which 65% agreed, 27% strongly agreed and 37% tended to agree (see figure 12, shown previously). And in response to a question about their views on the extent to which using genetic technologies in animals for food is a positive or negative development for society when this is done to improve animal welfare 21% of the survey respondents indicated 'very positive', 32% 'to some extent positive' (52% in total. See figure 15).

Figure 15: the extent to which using genetic technologies in animals for food is a positive or negative development for society when this is done to improve animal welfare



#### Unacceptable: Job losses

Certain case studies, particularly regarding genetic modification of Atlantic salmon which was presented to the group in Edinburgh, prompted concerns that genetic technologies could lead to job losses in the conventional industries that the products are competing against,

*'It would be unacceptable if it closes down fisheries, if a lot of people lose their livelihood or are negatively impacted for the profit of a single company or whatever, which there's always a risk of.'* (Edinburgh)

There was an acknowledgement that all technological advancements impact on existing industries, but participants wanted lessons to be learnt on how better to transition from one technology to another without decimating livelihoods.

### 3.3 Individual welfare



Acceptable: Prevent and cure diseases

As noted in Chapter 2 and under collective welfare in section 3.2, the prospect of genetic technology helping to prevent disease in humans was embraced as one of the most important positive outcomes for humans. As well as alleviating human suffering, the financial aspects of reduced healthcare budgets, previously noted in earlier discussions on global challenges, was recognised.

Acceptable: Transparency and choice

Common to all applications was a strong view on the need for transparency and clear information. Transparency includes information about why the technology has been developed, who has funded the research, who owns the technology, how it works, what it does, what the potential risks and side-effects are and what safe guards are being put in place. As one of the groups in London summarised their discussions,

*'We want to see who is using the technology, how, why and when as well as what the risks and side effects are.'* (London)

Transparency about human applications was seen as vitally important to individual welfare as everyone should have the freedom to choose whether or not to be genetically screened, whether or not to share the information that arises and whether or not to then be treated,

*'I wouldn't want to know if in twenty years I'm going to get Alzheimer's, so I'm in the no camp. And that should be my choice that I don't want to know that, not somebody else's. [...] And also it's a personal choice to act on it. I might be massively depressed but I still don't care if I'm going to die. Because I now know, you shouldn't force me to take action on that.'* (London)

*'If you've got a mutation and you choose not to treat it and have children? Maybe you'd choose not to have any children and not to have the treatment that should be your choice.'* (London)

The acceptability of applying genetic technology to food sources was quite heavily reliant on how clearly labelled and how traceable GM ingredients are. Clear labelling would enable informed choice to the consumer or not,

*'I'd probably start with the fact that people should be able to make choices and decisions if things are important, so if we want to eat genetically modified foods, and we're informed about them, shouldn't we at least have the option or the choice to eat them. Like if it's been tested and it's on the*

*market you don't have to buy it, but is there anything wrong with people choosing to buy it?'* (Edinburgh)

**Acceptable: To live more years in health**

There appeared to be greater enthusiasm for the application of genetic technology to humans to give us more healthy years, rather than expand our lifespan into the 100s and beyond. Living to 80s or 90s with more of your years in good health was preferred to the prospect of living longer under any circumstances because of the potential environmental and social impacts of a larger proportion of the population living longer such as pressures on the health service and the job market,

*'If it would be like for a person right now, with normal genetics and everything, who's 100 years old, for a genetically modified person, who's ageing has slowed down because of genetic engineering, this person has 100 years of normal years, has maybe the body of a 50 year old.'* (London)

In the survey respondents were asked, 'To what extent do you agree that genetic technologies such as genome sequencing and editing should be used in humans for prolonging life beyond current life expectancies?' The largest proportion of respondents were neither completely for nor completely against this idea with 39% agreeing to some extent that genome sequencing and editing should be used in humans for prolonging life, and 22% disagreeing to some extent (15% strongly agreed and 12% strongly disagreed). This suggests that the UK population has perhaps similar caveats to participants in the dialogue in that prolonging life if you can be healthy is appealing, whereas prolonging life whilst suffering the possible negative effects of old age and collectively being a drain on society's stretched resources is not as acceptable. This is explored further in section 4.1.3.

**Acceptable: Nutritional value retained or enhanced**

In the discussions about animal and plant applications for food there was concern that the nutritional value and taste of the genetically modified plants and animals might be reduced. As someone in Edinburgh said,

*'Flavour and health benefits, are you getting the same product or is one salmon better than another salmon?'* (Edinburgh)

This led to the view that in the context of individual welfare genetic alterations of food or animals for food should lead to a retention or enhancement of flavour and nutritional value.

The ability to improve diets, particularly in developing countries, by genetically altering a food product, such as rice or bananas, to be more nutritious was viewed positively by most participants. It was seen as a simple way to help populations to be healthier which provided strong economic, individual and social benefits,

*'In Africa bananas were so commonly used as a vegetable source, but they also found that there was a deficiency in nutrients that people in that area couldn't have so they were modifying the banana to give them the nutrient that they needed in their body, so I think that would be an acceptable use, to supplement, especially on a large scale, nutrients that are lacking.'* (Edinburgh)

### Unacceptable: Cosmetic uses

The survey showed a low acceptability of the use of genetic technologies for cosmetic uses across all applications, with marginally lower levels of acceptance for animal applications (57% strongly disagreed; 15% disagreed to some extent: 72% in total) compared to plant applications (51% strongly disagreed; 17% disagreed to some extent; 68% in total) and human (50% strongly disagreed; 18% disagreed to some extent: 68% in total), (see figures 16, 17 and 18, respectively).

For the most part, people endorsed genetic technologies to help eradicate disease but not to enhance human beings in terms of looks, strength or intellect. The phrases 'designer babies', 'playing God' and 'creating a superhuman race' were used negatively in this context.

In Norwich participants saw the use of genetic technologies to enhance human beings as raising a range of ethical challenges. As one participant said,

*'If you start genetically modifying human eye colours, if you don't conform to a certain look because your parents didn't have GM it could cause so many ethical issues.'* (Norwich)

And another Norwich participant felt that cosmetic enhancements is where a line should be drawn,

*'If we are using genetic technologies to create medicines for the benefit of the unwell that's a good thing. If we are using it to create a child who has a fashionable hair colour, that's a less good thing.'* (Norwich)

Some participants however, raised the point that it was social pressure, not the genetic technology that should be addressed to reduce individuals' need to achieve a certain look or status,

*'Treatment isn't the problem, society making people feel like they need to be enhanced, that's the problem.'* (London)

Participants really questioned the need to make fruit and vegetables that look good. They felt this was a waste of precious time and resources which could be spent on more pressing matters,

*'Why are we spending time developing fruit and veg that looks aesthetically pleasing?'* (Norwich)

Equally genome editing of animals for purely aesthetic reasons was not felt to have any value. Whilst recognising that selective breeding has taken place for many years, most participants didn't feel genetic technologies should be used to enhance animals for companions. As someone in Edinburgh said,

*'I don't agree with genetic modification of animals to create certain physical features in pets. It's unethical, unnecessary, just a non-essential novelty science.'* (Edinburgh)

These comments by two other participants in Edinburgh sum up the view of many expressing the concern that this is a waste of resources with no benefit to society. They saw it as a means to

generate profit for those developing aesthetic enhancements rather than for any positive societal benefit. Participants said,

*'To what end are glow-in-the-dark mice applicable? It's not as though you could release a mouse back into the wild that glows in the dark. It would become a massive target for birds at night. Beyond the capability to show that we can do it what's the benefit to it?'* (Edinburgh)

*'[I fear] it will be used ostentatiously rather than for genuine benefit, so the idea of designer babies and designer dogs, that it's used for profit rather than the greater good.'* (Edinburgh)

Figure 16: To what extent do you agree that genome editing should be used in animals for cosmetic enhancements (e.g. in pets such as fluorescent fish or micro-pigs)?

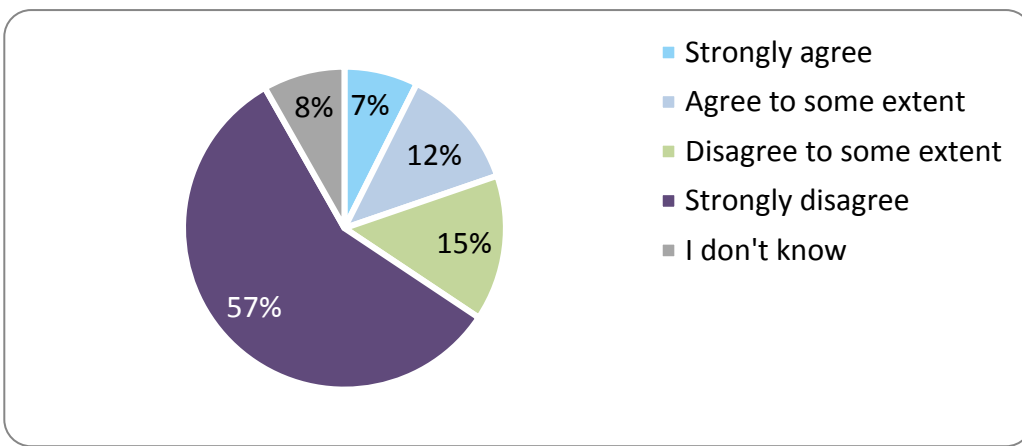


Figure 17: To what extent do you agree that genome editing and genetic modification should be used in plants for cosmetic reasons (e.g. to make vegetables look more attractive to the consumer)?

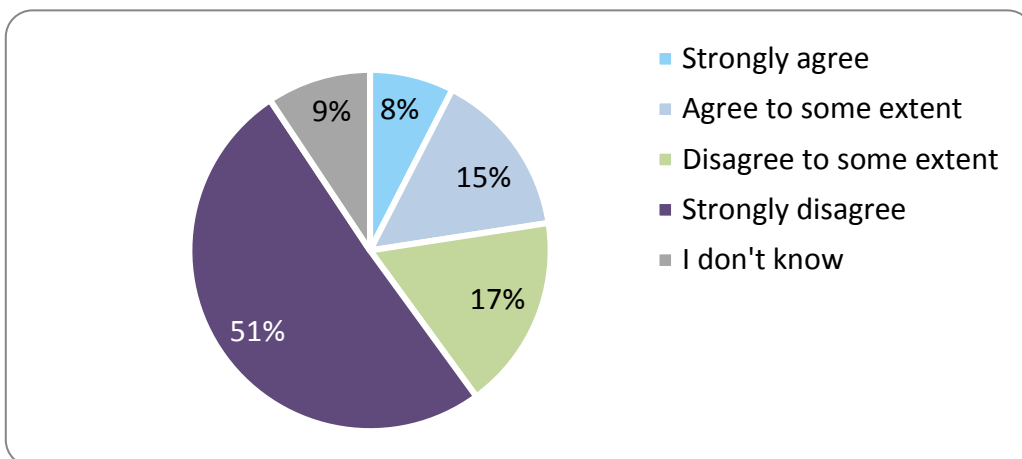
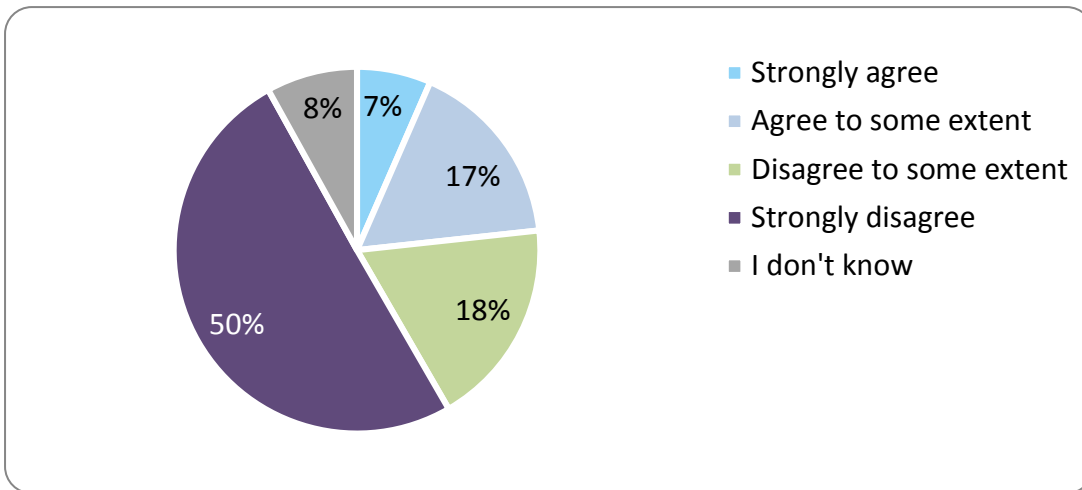


Figure 18: To what extent do you agree that genome editing should be used in humans for cosmetic reasons (e.g. changing a person's eye or hair colour)?



#### Unacceptable: More hedonistic, genetics can fix it

One conversation in London explored the 'what if' of people becoming more hedonistic because the consequences of their behaviour wouldn't shorten their lifespan,

*'If we identify the ageing genes, or the ones that kill you, you then get to decide whether you're going to live a party life, drinking, smoking, whatever, because you could always do a fix on that.'* (London)

*'And you just think you can do whatever you want because scientists can fix it.'* (London)

#### Unacceptable: Scientists prevented from working in genetics

The right to work in this field as scientists, unhindered by activists, was brought up in a few conversations. Participants felt that some forms of research might provoke protests, but there was the belief that if scientists are working within regulatory guidelines, they should be free to progress their research,

*'I would say it's unacceptable for society if scientists were to be attacked or persecuted for doing their job. You always see the news of someone with a mask on and a radioactive sign, throwing some sort of Molotov cocktail at someone.'* (Norwich)

#### Unacceptable: Regulations blocking access to experimental treatments

Whilst participants supported rigorous testing and trials for new technologies, there was also some frustration with the time it took to bring a genetic process to real world applications. Some felt they should have the right to access a treatment even if it wasn't fully approved, particularly if their life was at risk and this was the only potential treatment,

*'It's unacceptable for my individual welfare that I'm prevented from taking medicine that would help me, simply because it hasn't been approved.'* (Norwich)

*'If we can do it, it's unacceptable that we shouldn't. If we can cure spina bifida, why don't we? If we can cure cancer, why don't we? If it is purely a regulatory process that is preventing that technology from being used, maybe we ought to look at the regulation.'* (Norwich)

### 3.4 Environment



Acceptable: Adapting to or reducing the impacts of climate change

There was a widespread belief amongst participants, that genetic technologies are one set of tools among many worth considering to tackle global environmental and social issues such as climate change, food shortages and disease (see chapter 2). Most participants could see the potential for applying genetic technology to plants and animals in an effort to adapt to or reduce the impacts of climate change. Some participants had heard of cows being genetically modified to release less methane, others were positive about the role of plants,

*'It's acceptable if it offsets the damage that's already been done, for example where you have plants that are designed to help the environment, like trees that clean the water. I'm just going to put that out there, as long as it's been trialled properly.'* (Norwich)

Acceptable: Less waste and pollution

By using genetic technology to prevent or to treat diseases in human, animals and plants, participants could foresee a reduced need for medicines, herbicides and pesticides. This could in their view mean less pollution of the natural environment. In the words of participants in London,

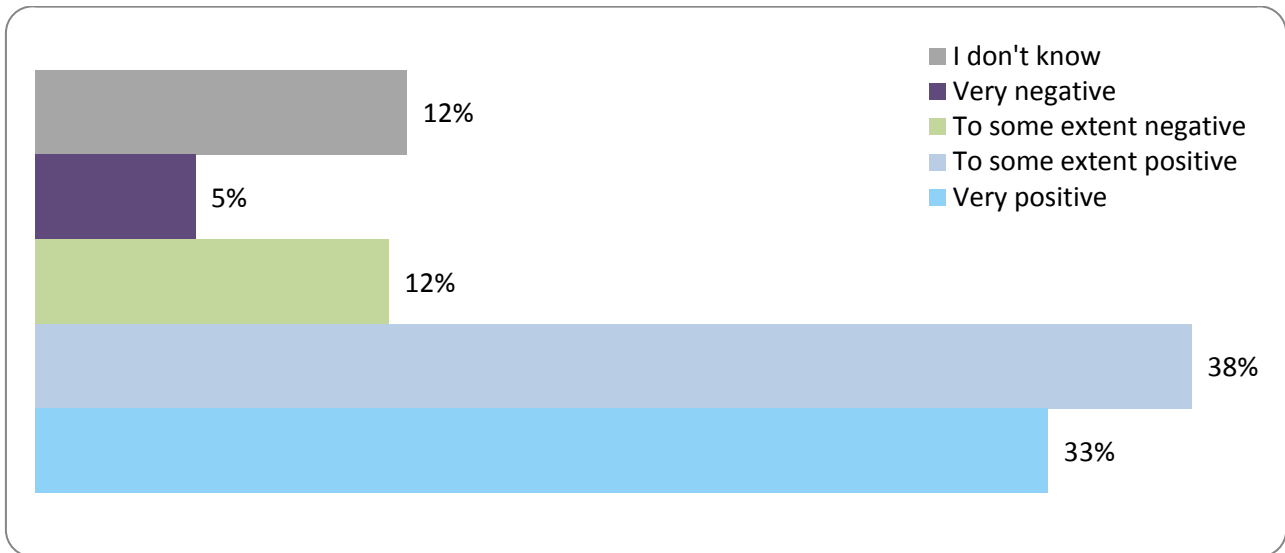
*'Surely if we're healthier, fitter, we've less need for medication, then there's going to be less medical waste, less factories, less everything that's bad for the environment that treats a person.'* (London)

*'Because presumably the impact on the environment from conventional medicine is getting quite big, whereas [the impact of] genetic technology could be comparatively smaller.'* (London)

Crops that are more resilient and therefore have inbuilt resistance that reduces the need for pesticides or herbicides were welcomed by most dialogue participants who shared the view that less use of chemicals in the environment is positive. This was in line with the view of survey respondents who were asked the extent to which it is positive for society to use genetic technologies in plants for food to reduce the environmental impact of agriculture (e.g. wheat that can use nitrogen from the air, reducing the need for adding nitrogen in the form of fertilisers). 71% of the population were either 'very positive' (33%) or 'to some extent positive' (38%) towards this statement suggesting a high degree of support for genome editing in plants for food for this purpose (see figure 19).



Figure 19: The extent to which it is positive or negative for society to use genetic technologies to produce plants for food when this is done to reduce the environmental impact of agriculture



Survey respondents were also asked the extent to which they felt it is a positive or negative development for society to use genetic technologies in plants for food to make crops compatible with chemical inputs (e.g. maize that is resistant to herbicides). 36% of the respondents said ‘to some extent positive’ and 22% ‘very positive’ (57% in total). This in some ways contradicts the desire of dialogue participants to reduce the need for chemicals in the environment, but is also in line with a general feeling that genetic technologies should be employed in making plants for food more productive to feed a growing population

#### Acceptable: Less land used for farming

Participants could see that genetic technology applied to plants could be helpful to the environment. They spoke about plants being genetically altered to grow more efficiently and envisaged the prospect of less land being needed for farming and the opportunity to turn that land back into natural habitats,

*‘On a positive note, if you were able to genetically modify crops so they’re more efficient, you can cultivate more efficiently, therefore you could actually increase animal habitats because you’ll be using less land, and wastage.’ (Norwich)*

#### Unacceptable: Reducing biodiversity

Eliminating species that are viewed as harmful to humans or not as efficient at producing food or energy as their genetically modified equivalents raised concerns about the possibility of reducing biodiversity and making us over reliant on corporate-owned species,

*‘What if by naturally selecting the plants and genetically modifying them we reduce the species available and actually make ourselves more susceptible to diseases and – what’s the word – if we make ourselves more susceptible by reducing the biodiversity, so we become more susceptible to any [diseases].’ (Norwich)*

#### Unacceptable: Changes to the food chain

There was some disquiet around genetic technology affecting the food chain. Some participants worried that eliminating a malaria carrying mosquito might have knock-on effects on other species that might rely on the mosquito as food,

*'So for instance say you've got rid of mosquitos... So what do we do in the case of that, do we keep DNA banks? And what are the implications if we lose species by doing this.'* (Edinburgh)

#### Unacceptable: Cross contamination

Unintended consequences due to lax containment concerned a few participants, particularly as people thought this kind of cross contamination could be irreversible and we may not have the know-how to deal with any negative outcomes,

*'We spoke earlier about bacteria and biodegradable petrol products that could be used to generate energy. [...] What if there is cross contamination and the environment we damage is our home environment?'* (Norwich)

*'Unacceptable is whatever change you're planning on doing jumps species [...] because that obviously wasn't planned for the other species.'* (Edinburgh)

#### Unacceptable: Taking national rather than a global view

Some participants felt that we should not be complacent about cross contamination by genetically modified crops being tested or grown in other parts of the world. They said that distance should not be seen as a protection from cross contamination or spread and that the UK should take more note of what is happening in other countries,

*'Things can't be looked at as a national issue when it comes to environmental issues it's got to be looked at as more of a global, because now we're so interlinked, you know. [It shouldn't be] just because it's on that side of the border it's not our problem...'* (Norwich)

#### Unacceptable: Weaponising animals

Some participants had seen a recent television drama that involved bees that had been modified to be weapons. This prospect of weaponising animals was rejected, as it was for weaponising humans on the grounds of using genetic technology for harm rather than societal benefit.

## 3.5 Regulation



From the very first discussions through to the end of the final session of the public dialogue participants raised questions about regulation and pondered what the role of regulation should be in the context of genetic technologies. In the words of participants,

*'At the end of the day somebody will have to decide what's appropriate, what's not appropriate, what is allowed, what's not allowed. Who does that?'* (London)

*'Who is going to regulate? Is it going to be a government that would look at what's best for everybody? Is it going to be a company that develops for money and for profit? If you've got enough money, can you buy whatever you want? The perfect child, whatever?' (London)*

A participant in Norwich summarised a generally held view that regulation is of prime importance with the pace of new developments gathering speed,

*'In that animation [contextual materials], the one thing that came out very strongly was that the technology is here, so we can't unmake that technology. It's now about how it's controlled and regulated, that's the issue because you're not going to unlearn that stuff.'* (Norwich)

Acceptable: Transparency, accuracy, safety and confidentiality

From the initial stages it became clear that a regulatory framework for genetic technologies needs to provide clarity about safety, accountability, the need for evidence of the accuracy and safety of processes and applications, with guidelines which are widely accessible,

*'Before things develop further you need to have a framework of what it's used for, who's going to monitor it and if something goes wrong what steps are in place to deal with it and inform the public? I was shocked when (the expert witness) said there's no world body that regulates it.'* (Norwich)

As a participant in Norwich explained, a clear regulatory framework would help alleviate the fear of the unknown in society,

*'The fears around the unknown and unintended consequences does come down to regulation and control. When you introduce a new medicine into society it has to go through rigorous testing that's been proven over time, and sometimes they get it wrong. This has got to go through a similar process.'* (Norwich)

Acceptable: Global regulatory framework

In all locations participants discovered that there is no global regulatory framework for genetic technologies,

*'I guess that different technologies have different rules and laws about this. What is not allowed in this country might be allowed in other countries, like genetically modified food.'* (London)

*'When I was talking to Dale [Sanders, expert witness] he told me there wasn't a global regulatory body. That's just a screaming error, there has to be.'* (Norwich)

They raised concerns about the uncertainty caused by Brexit,

*'One of my concerns is the UK coming out of Europe. We will have our own standards. We may or may not have the same standards as the rest of the EU. Whether they're the same as the US, or other parts of the developed world, or the less well-developed world. Who knows?'* (London)

*'There are global challenges around how these things can be regulated, especially in a world where we've got things happening like we're leaving the EU. We've got the potential for countries, like the UK, to go rogue and do it outside of an ethical framework.'* (Edinburgh)

There was some appetite amongst some participants for the UK to decide for itself on measures around food and crop regulation, which was seen as a benefit of Brexit,

*'What about if it's acceptable that as a country we still get the final say on what we actually grow, and what we do in our own country.'* (Norwich)

However, the further the dialogue progressed the more participants became convinced of the importance of a global regulatory body with recognition that this would not be easily achieved and should not be pursued to the detriment of making new discoveries on the uses of genetic technologies. They saw the need for global regulation primarily in the light of an increasingly globalising world, which through trade brings the health and environmental impacts of a potential lack of regulation in other countries to the UK,

*'What I do know is that a lot of this growing is going on in third world countries, right and then the regulations aren't so good over there. It's almost like it's somewhat acceptable to do that over there [...] but you couldn't do that over here. Because the world is getting smaller it can easily come here in terms of people travelling and all of that bringing food and seeds in and out.'* (Norwich)

Some noted that a global regulatory framework for genetic technologies would help to ensure that people will not be able to shop around for applications that suit them best as an individual but may not be approved in their own country,

*'You can't have a designer baby in the UK but you can go somewhere else and get it done. How do you stop that? I imagine each government will have their own rules and regulations.'* (Norwich)

The prevalence of the views on the need for a global regulatory framework for genetic technologies in the dialogue was tested and validated in the national survey. 81% of respondents answered 'yes' to the question whether they agreed that there should be a global regulatory framework. There is a significant difference between the 55+ segment (86% of whom answered yes) and the 18-34 and 34-54 segments (79% of whom answered yes). The survey also asked the extent to which people felt that research into genetic technologies in humans, animals, plants and microorganisms is conducted according to appropriate regulatory frameworks in the UK. It revealed that the older people are the more likely they are to agree strongly with this statement with significant differences between the 55+ segment (43% 'strongly agree'), 35-54 segment (34% 'strongly agree') and 18-34 year olds (29% 'strongly agree').

#### Acceptable: Stricter regulations for genome edited plants and animals for food

The national survey found that the UK public feels there is a need for stricter regulation of genome edited plants and animals for food to ensure the products are fit for human consumption. 47% 'strongly agree' in both categories, whereas 29% 'agree to some extent' in relation to animals for food (76% in total) and 33% in relation to plants for food (81% in total). Again, those in the 55+ age segment agreed with this more strongly compared to the younger age groups.

The dialogue showed that participants' concerns about the consumption of genetically modified products hinge strongly on perceptions of the potential health impact,

*'Even if it's cheaper I'm not sure I would eat it, how do we know it's safe?'* (Edinburgh)

This was balanced by comments from participants who said that food based on conventionally bred animals or plants may be no better option for good health due to the extensive use of antibiotics in animal rearing and pesticides and herbicides in crop growing,

*'I'm thinking that it's almost better, or it's less bad than some of the food, animal food that we do eat that's maybe injected with antibiotics and all things like that, so, is it better than that?'* (Edinburgh)

In the dialogue we therefore found split views on the need for stricter regulation, with some participants saying that genetically altered plants and animals for food should be subject to stricter regulation than conventionally bred variants and some that the standards for all food should be high and potentially brought up to the level required to regulate genetically modified food. As participants in Norwich said,

*'The idea wouldn't be lowering GM to traditional, it would be creating a consistent high quality standard.'* (Norwich)

This chimed with the view of another group in Norwich, in which some participants were surprised that conventional foods had little or no regulation around its cultivation and felt that the scrutiny of conventional food should be increased, however not to the lengthy processes currently used for genetic technology in food,

*'What's the difference though, between genetic technology crops and crops that have been cross-bred? At least the genetic technology crops have been through a process where they're checked.'* (Norwich)

*'I was going to say I didn't realise there were no regulations on the others [conventionally cultivated crops] so actually I think it's better that there are regulations there. I think the regulation should be across the board.'* (Norwich)

#### Unacceptable: Regulation that stifles progress

From a view that science is progressing rapidly and that it's hard to predict what the benefits for society will be of some of the developments, one of the groups in London raised the point that in their view regulation should not be too tight. They agreed that science should have freedom to act in terms of researching and testing genetic technologies with the rigorous regulation being applied once the technology was to be used in real world applications to treat or prevent disease for example,

*'What I would say is that they may as well just go all out, do all the different possible tests and things that they can do with it. But just use caution where actually applying it, because we still don't know*

*what it will do. I think, if we're positive about it and let them have a bit of free rein in terms of what they can do with it, it will actually be more beneficial, rather than imposing all these regulations on them.'* (London)

A participant in Norwich called this,

*'Safe but sane regulation'* (Norwich)

Unacceptable: Regulation unable to tackle black market

Concerns were raised about how effective regulation could be in hindering the black market around genetic technology or the emerging availability of DIY genetic kits. They mentioned drugs such as cannabis and the inability of laws or enforcement to curtail its production,

*'What about preventing people from doing that harm, because you can buy those kits now, so unacceptable in terms of- you can buy those kits, those CRISPR kits that you can mess around with yourself. How do you prevent people from creating some bacteria that has been edited in some way, when they don't even know [what the effect might be] because they're just messing around with it?'* (London)

*'If something becomes too expensive, people look for the cheaper options, and so they end up going on eBay, places like that, buying cheaper drugs from unscrupulous people. That's my fear with it, that if it's something you can buy on the black market and there's no mechanism in place to prevent that.'* (London)

## 4. Comparisons of applications and uses

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### Chapter 4 summary

In this chapter a comparison is made on the range of views on applications and uses of genetic technologies as applied to humans (London), animals (Edinburgh) and plants (Norwich). The findings are drawn from the survey results and discussions provoked by a review of the case studies selected on each of the three applications (see Chapter 1 figures 4 and 5) held to some extent in round 1 but for the main part in round 2 of the dialogue.

In **human applications** the case study on testing for genetic disorders raised comments around the following four main headings which are explored in the chapter. These are managing expectations; communicating the results; providing mental health support; and data protection and confidentiality. In discussing the case study regarding non-heritable genome editing for medical treatments dialogue participants focused on achieving a mindful balance in decision making; an ethical and honest approach; setting trends for medical advances and balancing individual and societal needs.

The main concern raised in the context of the third case study about genome edited human embryos was the issue of consent. The prospect of individuals making genetic choices that would influence all future generations was seen by many as both an opportunity and a threat. An opportunity to free future generations from a debilitating condition, such as cardiomyopathy, or as a threat to the right of the individual to choose for themselves. Dilemmas around consent included the impact on grown-ups and their offspring of not having had a say in the decision. The finding for survey respondents was somewhat different in that more felt very or somewhat positive towards using genome editing to correct a genetic disorder whether the correction would be inherited by any children of that person or not.

In applications to **animals** participants and survey respondents were supportive of genetic modification to prevent or cure human disease as long as the potential side-effects to patients are understood; NHS spending is fully justified; and the impact of genetically modified animals on the ecosystem is understood and minimised. There is much less support for the genetic modification of animals for food particularly when the modification is undertaken for the purpose of increasing the efficiency and productivity of meat production. The majority of dialogue participants and survey respondents do not agree with the cosmetic uses of genetic technologies to animals.

When considering applications to **plants** participants and survey respondents agreed that producing cheaper medicines which can reach the people that need them quickly is a positive development for society. They also believe that using genetic technologies to produce more nutritious crops to supplement dietary insufficiencies is to be welcomed as a route to feeding world populations. Equally using the technologies to protect crops from damage through, for example, late blight is an opportunity to take a global perspective as part of the solution to a sustainable food system. As in other applications the need for effective regulation was stressed as was the desire to prevent cross-contamination with related plants that have not undergone

genetic modification. Using the technologies for cosmetic enhancements to plants was not supported.

The view that people can see both opportunities and risks in the use of genetic technologies is summed up well by this participant:

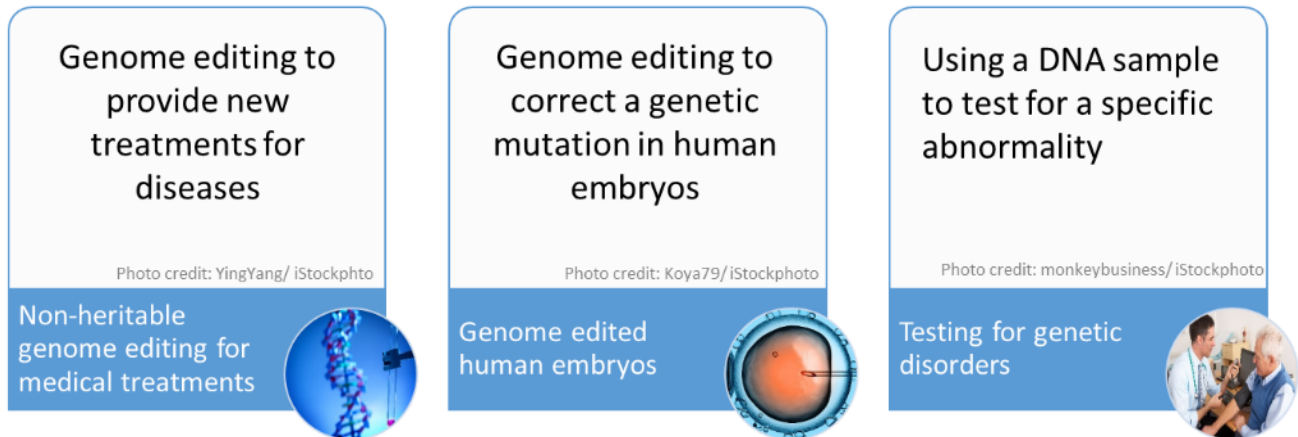




## 4.1 Human applications

Participants in London explored three human applications of genetic technologies:

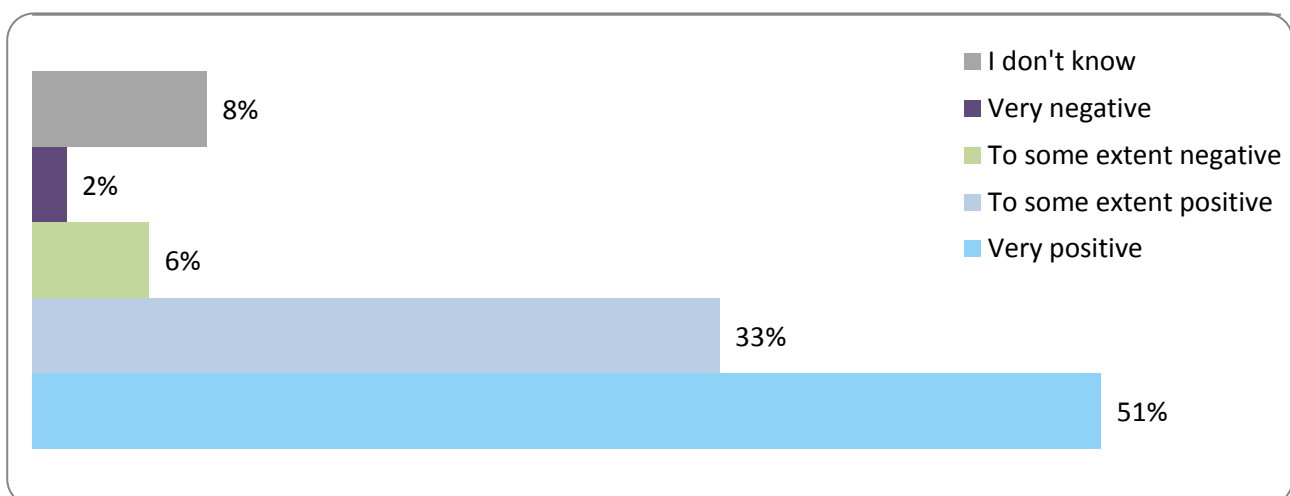
- Genome editing to provide new treatment for diseases, using the Baby Layla leukaemia case as an example
- Genome editing to correct a genetic disorder in human embryos which explored the example of hypertrophic cardiomyopathy
- Using a DNA sample to test for genetic disorders, with a focus on hypercholesterolaemia.



### 4.1.1 Testing for genetic disorders

In the national survey 51% of respondents indicated that using genome sequencing in humans as a way of identifying the risk of life threatening disease is a very positive development for society and 33% to some extent positive, 84% in total (see figure 20). We note there that there are no significant differences between the religious segments for this question.

Figure 20: The extent to which using genome sequencing in humans as a way of identifying the risk of life threatening disease is a positive or negative development for society



Discussions of the testing for genetic disorders case study in the dialogue led to a range of observations which highlighted particular concerns amongst participants around:

Managing expectations

Communicating the results

Mental health support

Data protection & confidentiality

Which are described in the following sections.

### Managing expectations

Participants raised questions about the accuracy of predictions made using genetic testing and felt expectations need to be managed on the basis of clear information about the probability of a genetic disorder developing. For example, in relation to the risk of breast cancer if one's mother has had breast cancer one participant said,

*'What are the risks of inaccurate results? Because I suppose any measures that you take to address your susceptibility to disease are going to be quite drastic, and when is it worth having a mastectomy, when it's a 90% chance or a 10% chance? It shouldn't be 'You're going to get breast cancer, let's give you a mastectomy; whoops, we got it wrong.'* (London)

Some participants highlighted the need for accurate information about what conditions can and can't be tested for so that expectations can be managed,

*'Most cancers and problems are caused by genetic mutations after birth, so you're not going to catch everything. So to say funding it [genetic testing] will solve everybody's problem, and get rid of all cancers; you're not. And that's a problem. We can't give people expectations which aren't reasonable.'* (London)

*'A genetic disorder, or an abnormality, is that absolutely anything, or is it things like breast cancer or that you might get a mole on your face? Do you know what I mean? It's saying we can test for 'it' but what is the broader definition of 'it'?'* (London)

### Communicating the results of genetic testing

Participants appreciated being made aware of treatable conditions. In the words of one,

*'If you were told, after having genetic tests, that you may have historical diseases that may make your life hard, and you can eradicate it, then you would think it's a good thing, because you're being told that.'* (London)

However, they disliked the possibility that a person could be screened for a range of conditions and told about them even if not all of them are treatable,

*'The much harder part [of genetic testing] is explaining what it means to you to have the gene and what, if anything, you can do about it.'* (London)

*'Certainly to be told that you've got something but we can't do anything about it, that's even worse than not knowing. I don't like the idea of being told when I'm young that I've got something I can't do nothing for.'* (London)

### Mental health support

Genetic testing was seen by a number of participants as being highly likely to have mental health implications for some people. Being told that you have a predisposition to a particular condition they felt could put people in a vulnerable situation, where they may be asked to make significant choices without being sufficiently emotionally stable. The mental health challenges of living for longer were also raised,

*'It would be a massive shift. I don't know what the answer is, but we're just presuming that being healthy and living longer, we'll all be happy. Actually somebody might be like massively healthy and 110, but morbidly depressed.'* (London)

Participants who discussed this wanted to see mental health support factored in to the roll-out of genetic technologies.

### Data protection and confidentiality

Participants also expressed concerns about the potential impact of screening results on insurance premiums in line with current practice in which policies are more expensive for an individual who has particular health issues,

*'If somebody says you've got the genetic possibility of developing breast cancer, therefore we're not going to insure you.'* (London)

This fitted with a wider discussion about confidentiality in which it became clear that the case study raised questions about how data derived from genetic testing are protected both in the public health domain and in the context of commercially available DIY testing kits,

*'I had a question about the data, and if your genetic data is protected under UK law as personal information, and whether [when] you've paid £750 [for a test] you therefore immediately lose the right to your data? Would that be part of the deal, if you like?'* (London)



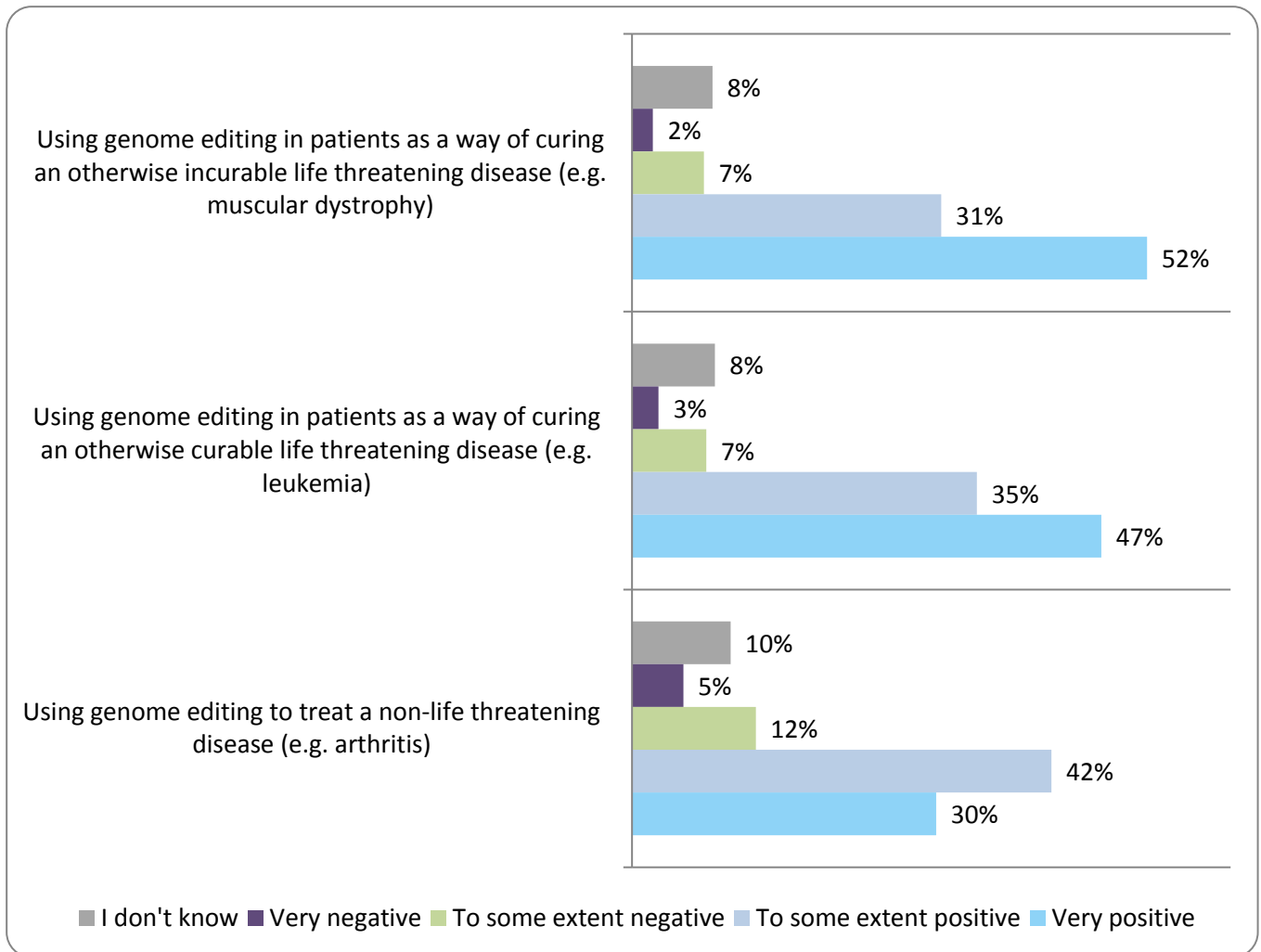
Figure 21: Visuals created by London participants on testing for genetic disorders

### 4.1.2 Using genome editing in patients

In this section we describe the views on a range of uses of genome editing in humans, including somatic and germline processes as explored by survey respondents and dialogue participants.

### Genome editing as a way of curing life threatening disease

Figure 22: Human applications - the extent to which the developments listed can be seen to be positive or negative for society



As figure 22 demonstrates the survey showed that there is support in society for the use of genome editing to cure *life threatening diseases*. A majority (83%) of the respondents indicated that using the technology to treat *otherwise incurable* life threatening disease such as muscular dystrophy is ‘very positive’ for society (52%) or ‘to some extent positive’ (31%); equally, a majority (82%) indicated that using genome editing in patients as a way of curing an *otherwise curable* life threatening disease such as leukaemia is ‘very positive’ (47%) or ‘to some extent positive’ for society (35%).

With 73%, the percentage of those who see genome editing to treat a *non-life threatening disease* such as arthritis as ‘very positive’ (30%) or ‘to some extent positive’ for society (42%) is somewhat lower. Nevertheless the survey demonstrates that people are broadly supportive of the use of genome editing to treat diseases whether life threatening or not. This is in line with the dialogue finding that participants feel positive towards genetic technologies being used to alleviate suffering.

### Non-heritable genome editing for medical treatments

In the dialogue participants discussed the case of Baby Layla (life threatening leukaemia) for whom all other treatment had failed. Participants raised four considerations which are explored in the following section:

Only option

Ethical &  
honest  
approach

Setting the  
trend

Balancing  
individual &  
societal needs

There was consensus amongst participants on the positive benefits of using genome editing for an otherwise curable disease if it is the *only option* left to save a human life,

*'It's completely understandable that as a parent you want to go down this route. Nothing ventured nothing gained.'* (London)

They implied that all other options should be explored first and that genetic technology should be a final resort as long as the technology isn't tested fully to understand what the potential side effects might be,

*'We need to be careful as we don't fully understand how Baby Layla will be in 10 years' time, if she will develop any negative side effects.'* (London)

The poster exercise in which participants made a statement of an imaginary meeting they had attended with a range of stakeholders to discuss their consideration of the case study demonstrated that participants felt that it is important in a case as Baby Layla's to achieve a *'Mindful balance'* based on an ethical and honest approach including a clear consideration of the pros and cons of treatment. The group recognised and welcomed the opportunities non-heritable genome editing for medical treatment can bring. They used the words *'Setting the trends'* to express that they were happy for the scientific community to lead the way as long as there is effective regulation in place which doesn't hinder technological advances - *'Don't regulate to death'* - and balances the needs of individual patients with a desire to allow science to progress and help *'Change the world'*.

In the discussion around the poster exercise participants said that careful evaluation of the process is essential, taking in to account alternative options and circumstances as well the benefits for society,

*'Can I just put in a bid for being cautious and treating future illnesses and issues from scratch and evaluating. Rather than thinking; 'it worked, it was successful for a different disease, that this genetic treatment worked with Layla', and being too go-ahead next time. [...] They should be cautious and evaluate on the same basis about whether they've tried other things, whether this is a good use of resources, whether it has clinical benefits. A cautious approach to evaluating future uses.'* (London)

The group called for a *'Clear vision so we feel safe in the industry'* (see figure 23).



Figure 23: Visuals created by London participants on non-heritable genome editing for medical treatments

### Genome editing to correct a genetic mutation in human embryos

The main concern raised in the context of the case study about genome edited human embryos was the issue of consent. The prospect of individuals making genetic choices that would influence all future generations was seen by many as both an opportunity and a threat. An opportunity to free future generations from a debilitating condition, such as cardiomyopathy, or as a threat to the right of the individual to choose for themselves,

*‘Could it straddle both sides that an unacceptable cost to individuals in society could be your parents or your grandparents making decisions for future generations? All the things they’re afraid of they can have rooted out of their gene pool, and so, I don’t know if that’s acceptable or unacceptable.’* (London)

Dilemmas around consent included the impact on grown-ups and their offspring of not having had a say in the decision, which showed that heritable genetic corrections are not supported by all,

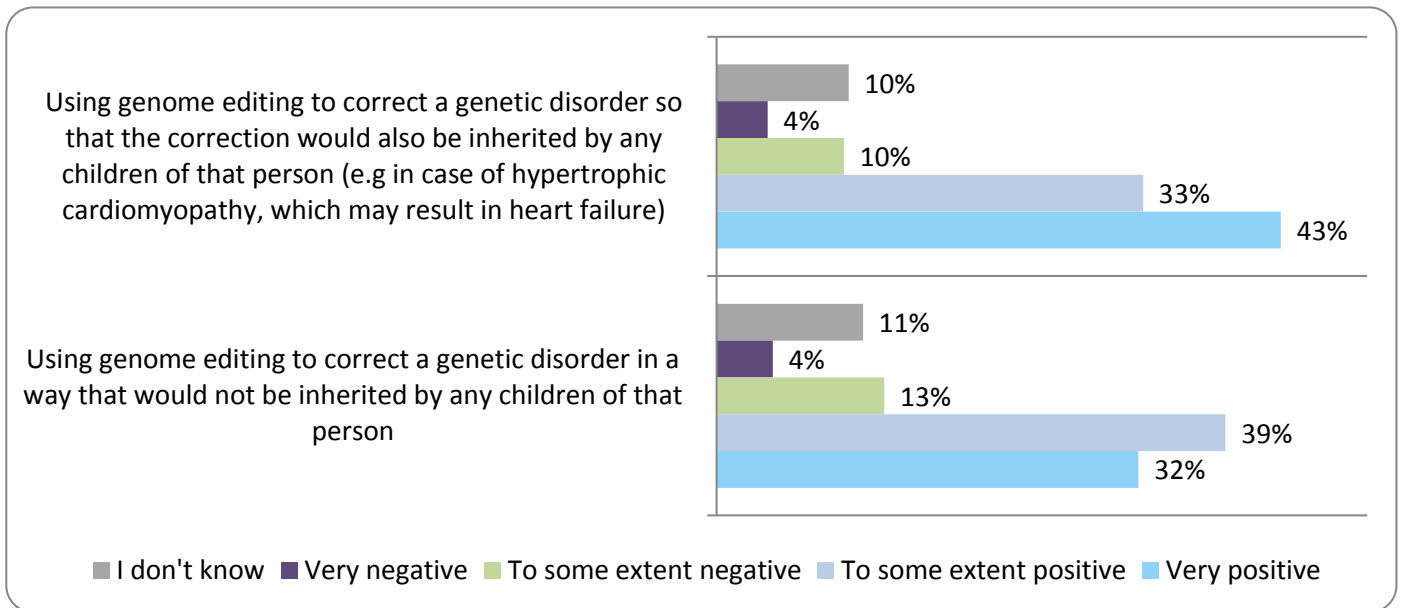
*‘The next generation won’t have a say, really. If something is already altered, and they are born as a result, they haven’t got a say in what is happening to them, maybe that’s a step too far.’* (London)

*‘How would I feel, knowing that someone else has basically tampered with me? And if we’re talking about laser eye surgery, well that’s a choice you make as a grown person, but if that choice is already made for you.’* (London)

The survey (figure 24) demonstrated a somewhat different finding. Genome editing to correct a disorder so that the correction would also be inherited by any children of that person was seen as

'very positive' to society by 43% and 'to some extent positive' by 33% (76% in total). In comparison, 32% said that the use of somatic processes in genome editing so that the correction would not be inherited is 'very positive' for society and 39% 'to some extent positive' (72% in total).

Figure 24: Extent to which the developments can be seen to be positive or negative for society



The poster exercise around this case study (figure 25) showed that, as far as the dialogue participants were concerned, it is important to explore all alternative options before going down the route of genome editing of human embryos. Considerations of the cost to society of more people living longer, regulation and choice mattered to participants as did an open mind to alternative options both in traditional medicine and genetic technologies. As expressed in one poster, *'The world is ours to explore'*. Participants also used phrases such as *'Meet the winner'* and *'Labour of love?'* to describe individuals freed of a genetic disorder and the endeavour of working in this field.

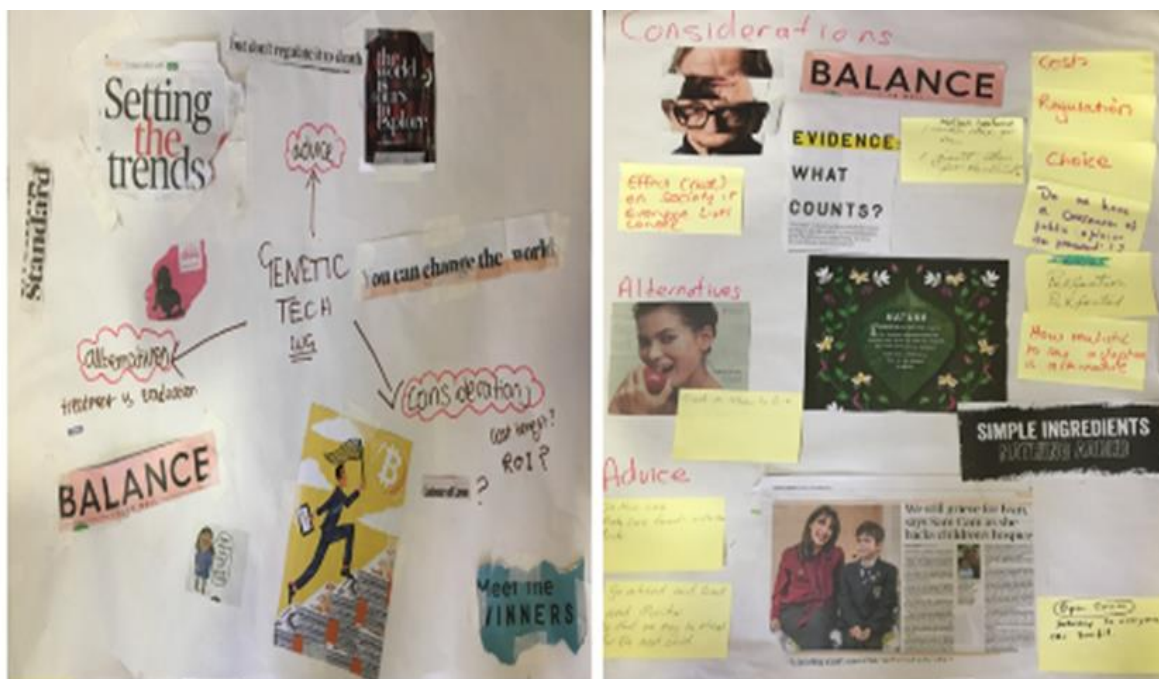


Figure 25: Visuals created by London participants on genome edited human embryos

The opportunity, caveats and concerns expressed in the dialogue regarding this case study are summarised in figure 26.

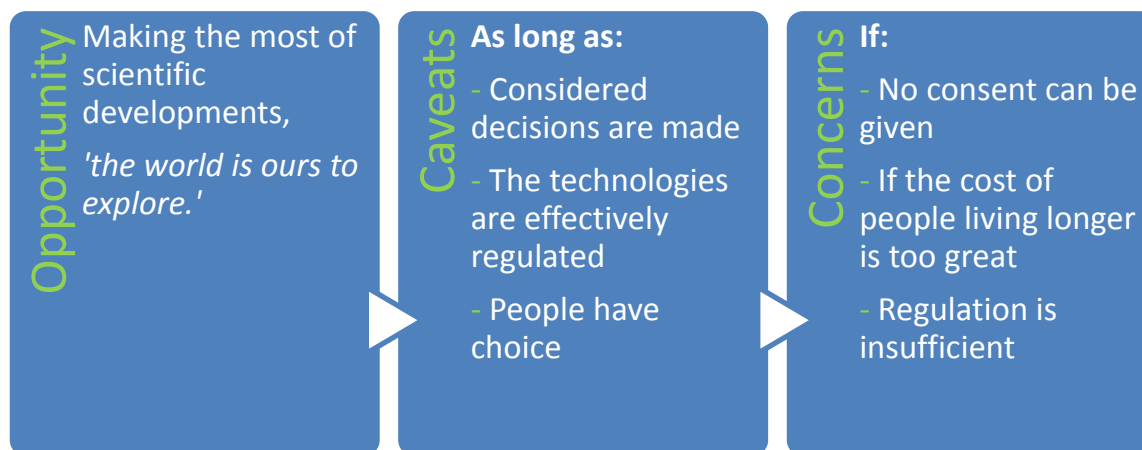


Figure 26: Opportunity, caveats and concerns in relation to genome editing to provide new treatments for disease

In each of the case studies demonstrating uses of genome editing there was a view in the dialogue that it is important that patients make a considered decision about the treatment. This will be aided by clear and comprehensive information provided by the medical profession. This was seen as a responsibility for patients and their families as well,

*'I think just completely understanding what you're getting yourself in for. Because it is, potentially, completely irreversible. You're not taking medicine, you're changing your genes, and you're changing what makes you. Once it's done, you can't go back. So just understand that what you're doing, you're doing it.'* (London)

#### 4.1.3 Using genetic technologies for prolonging life beyond current life expectancies

Just over half of the survey respondents indicated that they agree with using genetic technologies for prolonging life, 15% 'strongly agree' and 39% 'agree to some extent' (54% in total, figure 27). In the dialogue views were split equally about the extent to which living longer is positive. Participants who were positive about the prospect of prolonging life spoke about the benefits to society of learning from people with long life experience and of people who are healthy working for longer and contributing taxes to the country. There was also the view that people might be more aware of their environmental impact if they lived longer. As someone in London said,

*'If you can make yourself live longer on this planet, people might be a little bit more careful with it.'* (London)

There appeared to be greater enthusiasm for the application of genetic technology to humans to give us more healthy years, rather than expand our lifespan into the 100s and beyond. Those who saw the negative consequences talked of a world that is already experiencing scarcity (e.g. drinking water) so the prospect of a larger population caused by people living longer was seen as a threat to the quality of life,



*'If curing or treating life threatening diseases now becomes viable, you will then suddenly see an increase in the population. [...] One of the reasons why there is so much poverty and people are dying is this overpopulation, in comparison to say, a hundred years ago.'* (London)

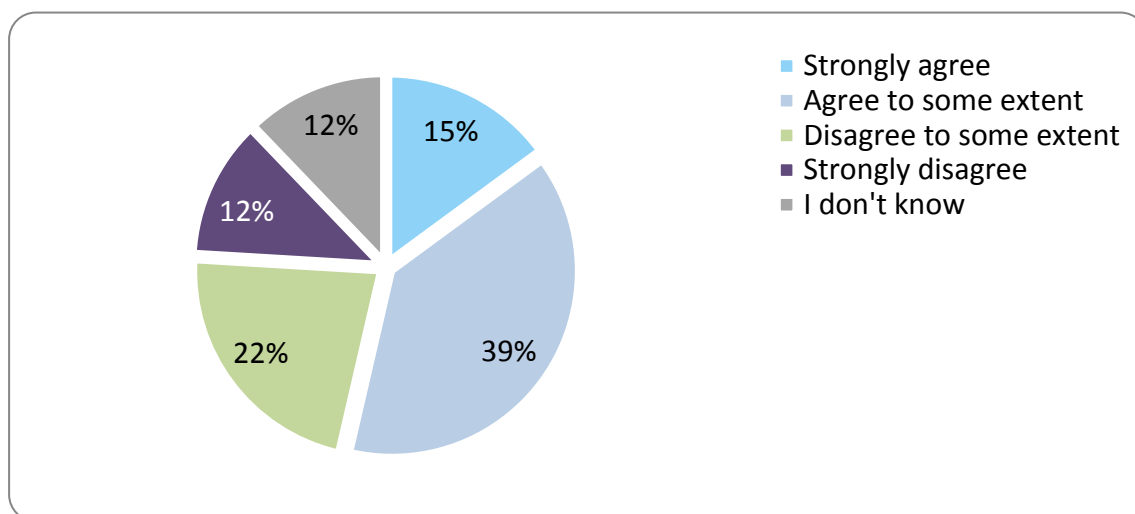
People expressed concerns about the impact on our current standard of living, due to pension deficits, an increased pressure on housing and the NHS,

*'If we have too many people, we'd have to lower our standards of living, if everybody lives another five years. We'd run out of space and food, resources.'* (London)

*'It's everything, it's even housing and you're talking about pensions and the NHS. Can we house everybody? We keep having babies at the same rate but it's not going off at the other end.'* (London)

In the survey for the most part no significant differences in views depending on respondents' age have been found except in the prolonging life beyond current expectancies question. On a decreasing scale, 21% of 18-34 year olds felt that using genetic technologies for this purpose is a 'very positive' development for society, 14% of 35-54 year olds, and just 10% of those who are in the over 55 segment. This ties in with the dialogue finding that there was more support generally for people to live longer in good health rather than always live longer in whatever circumstances.

Figure 27: Using genome sequencing and editing should be used in humans for prolonging life beyond current expectancies



The opportunities and concerns that arise for participants in considering the use of genetic technologies to prolong life beyond current life expectancies are summarised in figure 28.

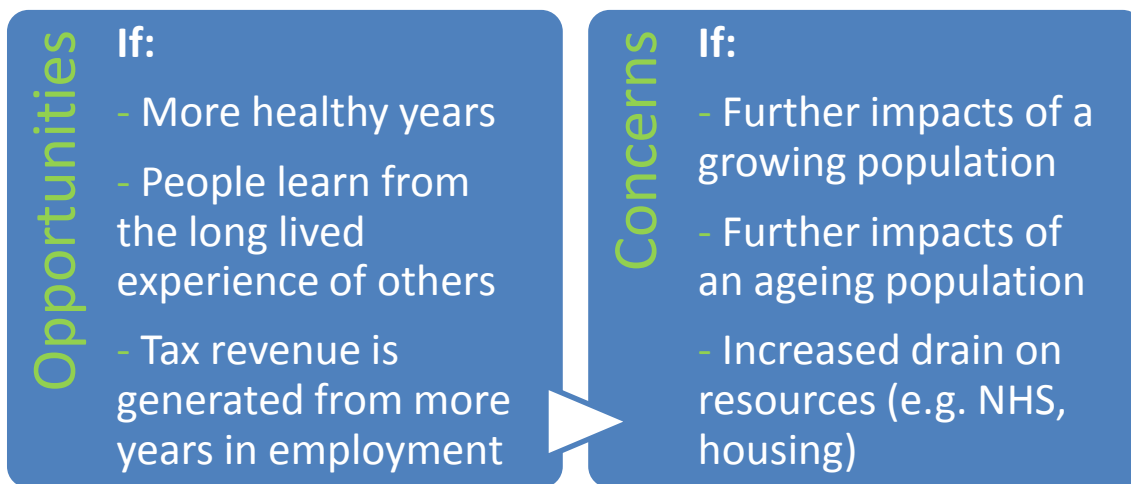


Figure 28: Opportunities and concerns in using genetic technologies for prolonging life beyond current life spans

#### 4.1.4 Using genome editing for cosmetic reasons or enhancement of abilities

As described in section 3.3 and shown in figures 16-18 in the section on individual welfare we find that there is little support for the use of genome editing for cosmetic reasons in either the public dialogue or survey. As figure 18 shows, 50% of the population strongly disagree with these applications to humans and 18% disagree to some extent (68% in total). We note a difference here in relation to survey respondents' age with only 39% of 18-34 year olds strongly disagreeing with using genetic technologies in humans for cosmetic or enhancement reasons compared to 51% of 35-54 year olds and 60% of those in the 55+ segment. In an age of tattoos, piercing and body adaptations it is perhaps not surprising that there is more tolerance for this application in younger age groups.

##### Concern for further divisions in society

Using genome editing for cosmetic reasons or for enhancing abilities was perceived by the majority of dialogue participants as unacceptable for fears of creating further divisions in society,

*'Any enhancement of the human performance in terms of how strong they're going to be, or how beautiful, or how clever, that is just not acceptable, because that would be unnecessary in the terms that it kind of creates a completely new world.'* (London)

*'If that technology is allowed, it would probably be accessible only to extremely rich people, and if they were allowed to use this technology, it would create an even bigger divide in society.'* (London)

One group discussed the fact that the use of doping in sports is not allowed and agreed that for similar reasons enhancement of abilities is a no-go area,

*'Like at the moment doping is strongly forbidden, so then you're kind of creating humans who are more beautiful, stronger, it's not fair for them to compete with other levels.'* (London)

These findings chime with the national survey, in which 34% of respondents strongly disagreed and 25% disagreed to some extent with the statement that genome editing should be used in humans to enhance abilities (60% in total).

### World of imperfect perfection

Discussions about the use of genetic technology for cosmetic reasons or enhancement of abilities also sparked discussions about the notion of perfection and imperfection and who decides what disease or disability. One participant spoke about a friend who has a son with cerebral palsy who said,

*'Who is anybody to say that her life or her son's life is not good enough? They love him the way he is, they love their life, and they've had many experiences through having him that they wouldn't have had otherwise.'* (London)

The views of dialogue participants and survey respondents on genetic technologies applied to humans can be summarised as (figure 29):

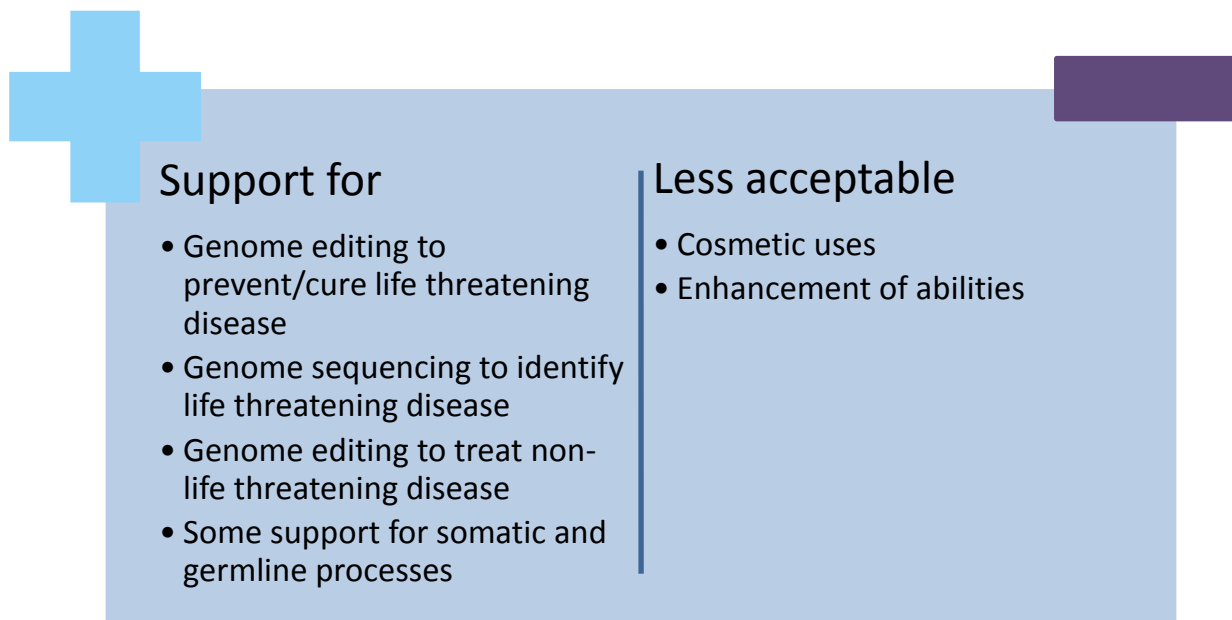


Figure 29: Areas participant support and those they find less acceptable in human applications

## 4.2 Animal applications

Participants in Edinburgh explored three case studies for animal applications of genetic technologies:

- Genetic modification of mosquitos to reduce the risk of vector-borne diseases;
- Genome editing to make viral DNA inactive in pig organs for use in human transplants;
- Genetic modification to develop a variety of Atlantic salmon.



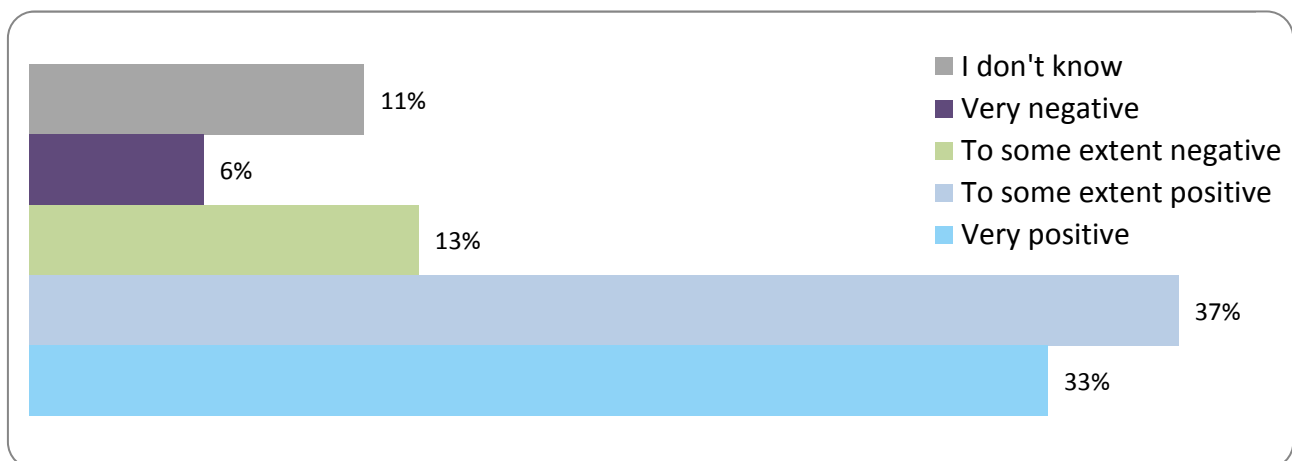
### 4.2.1 Using genetic technologies in animals as a way of preventing human disease

In this section we describe the views on a range of uses of genome editing in animals to prevent human disease as explored by survey respondents and dialogue participants.

#### Use of genetic technologies to reduce the risk of vector-borne diseases

The survey shows that 33% of the population is very positive and 37% to some extent positive about the use of genome editing in animals as a way of preventing human disease even if the ecosystem might be affected (71% in total, figure 30).

Figure 30: Using genome editing in animals as a way of *preventing* human disease (e.g. using genetically modified mosquitoes to limit the spread of malaria, dengue and zika), even if there may be an effect on the ecosystem.



In the dialogue the majority of participants who discussed the case study on the use of genetic technologies to reduce the risk of vector-borne diseases agreed this is a positive development for society. The example was mentioned unprompted by a number of participants in the early stages of the discussions before the case study was introduced,

*'My hope is that scientists will be able to genetically modify some animals to ensure that diseases that are currently spread from the animal to the human can be eliminated or reduced.'* (Edinburgh)

Some participants were uncertain that human need should take precedence over sustaining animal populations,

*'The measures they're trying to take to stop mosquitos spreading viruses, [...] I was thinking about the justification of trying to wipe out a species just because it badly affects us.'* (Edinburgh)

The majority of dialogue participants felt positive about using genetic technologies as a way to prevent human disease as long as there is equity of access to the technology,

*'As the highest rates of malaria, dengue fever and like zika are in the poorest countries I would definitely raise a moral issue that this should be seen more as a humanitarian project and is not for profit as these countries can't afford even basic provisions for mosquito control.'* (Edinburgh)

The group's main concerns centred around the ownership of the technology and fears of large corporate-type monopolies, the impact on the ecosystem and the safety of the technology,

*'The ownership of the technology, like Monsanto... I would advise the Government/policy makers not to allow the businesses to be in control.'* (Edinburgh)

*'So people know what a genome is, and by alternating it what are we actually doing and how that might impact on the ecosystem.'* (Edinburgh)

*'Ensuring the safety of research so it doesn't get out of the lab before it is fully tested and deemed safe.'* (Edinburgh)



Figure 31: Visuals created by Edinburgh participants about the use of genetic technologies to reduce the risk of vector-borne diseases

The sentiment that using genetic technologies in animals to prevent vector borne disease is an opportunity for humanity was expressed through statements in the poster created by the group (figure 31), including *'We can feed the world!', 'I'm thinking of the future of mankind', 'Broaden your mind', 'You'll be amazed', 'Mosquitos wiped out'*.

Participants expressed the view that science is *'Pushing the boundaries'* and that it is important to embrace advances for a better a more equal and healthier world, *'We no longer need to put up with misery, we can alter the way we live and tackle hunger and disease.'* (Edinburgh)

As in other case studies, participants in this group stressed the importance of education, which they illustrated with the word *'Keeping you in the picture'*. In earlier discussions the group had said they would like the scientific community to,

*'Take heed of public concerns, analyse initial feedback and come back to them with new findings.'* (Edinburgh)

*'Make it simple and relevant so there is clear understanding of the issues, the pros and cons of using this technology.'* (Edinburgh)

Figure 32 provides a summary of the opportunity, caveats and concerns around the use of genome editing of mosquitos to reduce the risk of vector-borne disease.

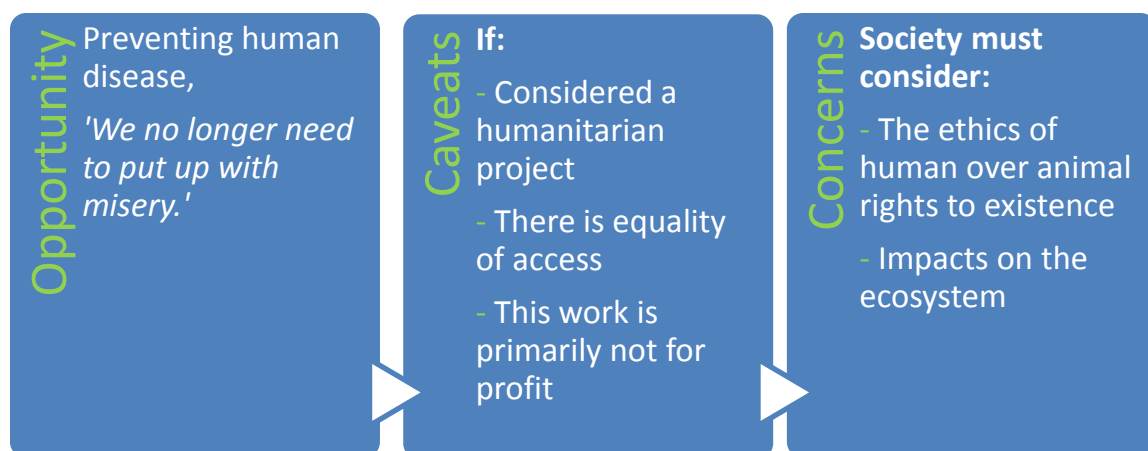
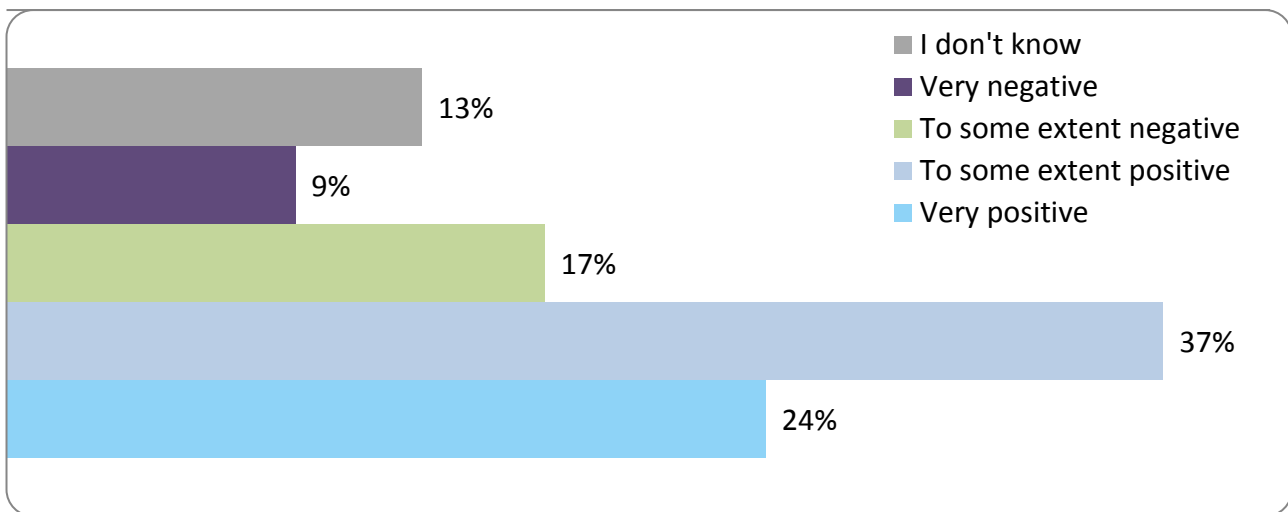


Figure 32: Opportunities, caveats and concerns in using genetic technologies for reducing the risk of vector-borne diseases

#### 4.2.2 Using genome editing in animals as a way of curing human disease

37% of respondents to the survey indicated they consider using genome editing in animals as a way of curing human disease (for example adapting pig organs so that they are suitable for use in human transplants) as 'to some extent positive', and 24% 'very positive' (61% in total, figure 33).

Figure 33: Using genome editing in animals as a way of curing human disease (for example adapting pig organs so that they are suitable for use in human transplants)



### Opportunity

In the dialogue participants were fairly positive about the opportunity provided by the use of genome editing to make viral DNA inactive in pig organs for use in human transplants. In the poster exercise (see figure 34) they used words including *'On a mission to save humanity'* to express an appreciation for a solution the technology can bring to the 6,500 on the waiting list for organ donations and the potential improvements to quality of life,

*'So we've done our research, so we're on a mission to save humanity. It needs to be done, it needs to be done and from the technology side of things it's the dawning of a new area, we're using the technology and you will be amazed at what we will achieve.'* (Edinburgh)

*'Yeah that was just the quality of life that you could be given, you know that you could have if you got given a new organ and things like that.'* (Edinburgh)

There was excitement about the technology as part of a range of research options and the group advocated for ongoing research in stem cell solutions as well,

*'We've put 'on a mission to save humanity' because it's going to address the issue of the lack of organs for transplantations. We're also asking the public to broaden their minds and open it up to the use of pig organs that are going to be genetically modified, although we also want to use the technology to try and explore stem cells a little bit more.'* (Edinburgh)

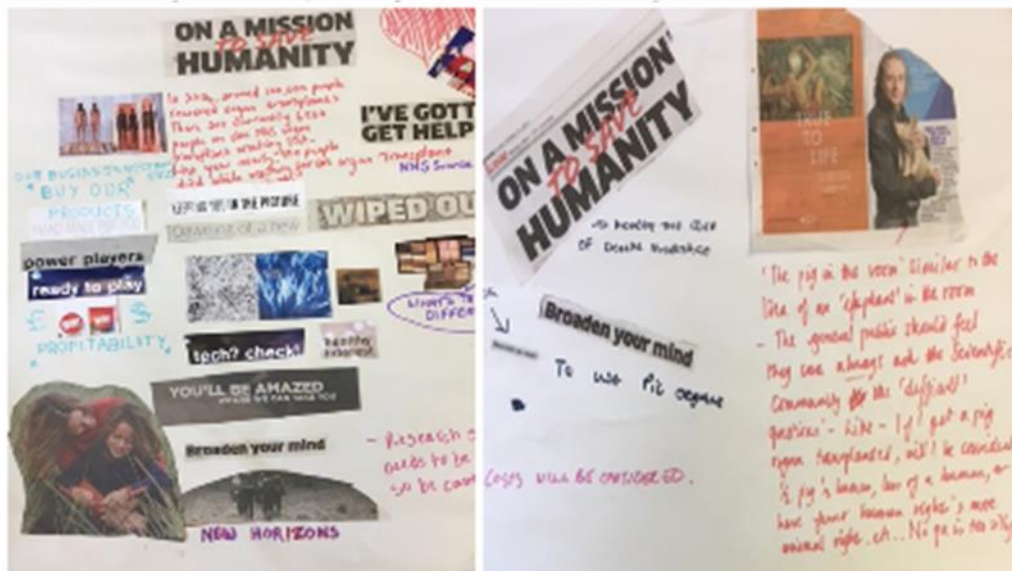


Figure 34: Visuals created by Edinburgh participants on the use of genome editing in animals to cure human disease

### Caveats

The group discussed a range of caveats. One of their concerns was the lack of evidence about the potential long-term side effects for patients following the transplantation of a genetically modified pig organ,

*‘Obviously because right now it’s quite new, it should be approached with caution because we don’t know the long term effects.’* (Edinburgh)

Funding of the research and application was debated vividly, with the majority of participants agreeing that the money required for development should not add to an already strained NHS budget. They said they would like to understand better what the cost-benefit ratio is in terms of saving human lives through the use of this application compared to other diseases including cancer,

*‘From an NHS perspective all I see in the media at the moment is budget, budget, budget. Everything is getting cut. So now you’ve come up with this new technology of heart implants, how would you prove to the general public the money that will be spent on all this research and all these farms of pigs, how can you justify that? When we’re talking in statistics, we’ve got 6,500 people on the list but there’s more people probably have cancer or other genetic diseases.’* (Edinburgh)

There was a view that resources for research shouldn’t be taken from an already stretched NHS budget or research programmes that benefit other patients,

*‘We want to consider the costs involved for the NHS and also that no vital funds will be diverted from other research programmes or medical programmes to fund this.’* (Edinburgh)

It was important to participants that the application doesn’t have a negative impact on the environment and that checks and balances are in place to ensure animal welfare isn’t negatively affected,



*'How will the use of GM pigs impact on future generations and their ecosystems?'* (Edinburgh)

*'Well again with regards to safety, what checks and balances are in the system, in governmental and even across the world to safeguard?'* (Edinburgh)

*'It needs to be a transparent process so that everybody knows exactly what's going on and you're not hiding anything away about the effects on the animal donors.'* (Edinburgh)

This led to a conversation about regulation and the protection of patient rights, in which it became clear that for participants in the dialogue a clear accountability structure for patients is essential to gain trust in the application,

*'How's the legislation worded so that it protects human rights, people like me who get those transplants, if something goes wrong for instance, how are we protected, how do you trace them?'* (Edinburgh)

#### Social considerations

The case study group discussed how humans with an animal organ may be viewed by society and showed concerns about potential marginalisation of the carriers of animal transplants,

*'Will those patients given GM pig organs be treated any differently by society as a whole or even be 'ostracised' in some cultures as a result of using pig organs?'* (Edinburgh)

The group linked this discussion to a need for transparent two-way communication in a space where members of the public feel safe to ask scientists and policy-makers any questions they feel are relevant,

*'What's the elephant in the room? What's the pig in the room? Questions that are difficult to ask, so the general public can always ask the scientific community the difficult questions no matter how silly and the scientific community and the government should always be held to account to the public and not feel that they can shirk the responsibility to answer those questions, so no question is too silly.'* (Edinburgh)

Participants drew on the use of genome editing to make viral DNA inactive in pig organs for use in human transplants as an example of a context in which transparency and communication is essential,

*'Like if I get a pig organ transplanted will I be considered half pig half human, less of a human, half my human rights? You know these are not silly questions this is how you'd be viewed perhaps secretly and it could affect your life and your life chances so you need to ask questions no matter how difficult.'* (Edinburgh)

This led to the conclusion that openness and honesty is important to gain the public's confidence in the application,

*'Whoever is carrying out the research, whoever's funding it, until the results are published, whether it works or doesn't work, just make sure that the public is kept in the loop.'* (Edinburgh)

The opportunities, caveats and concerns regarding using genome editing to make pig organs suitable for human transplants are summarised in figure 35.

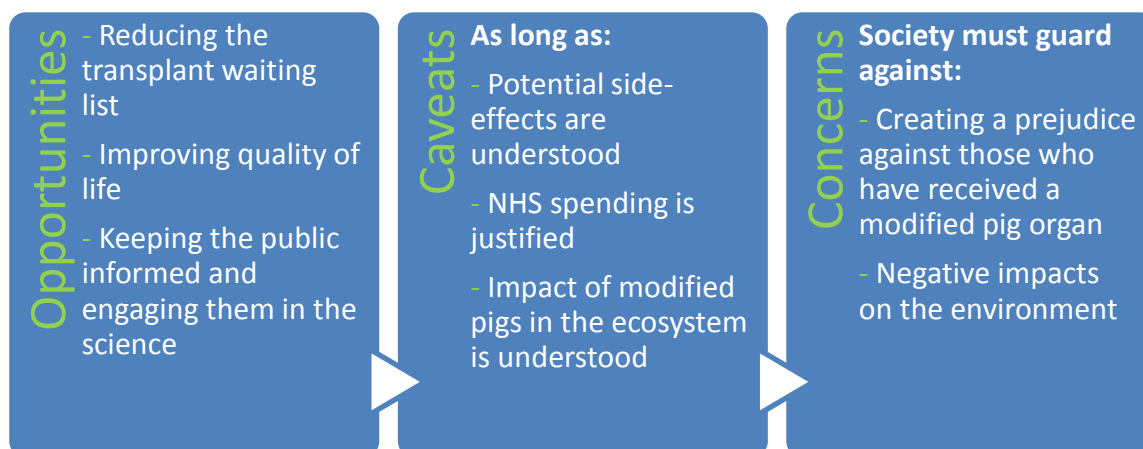
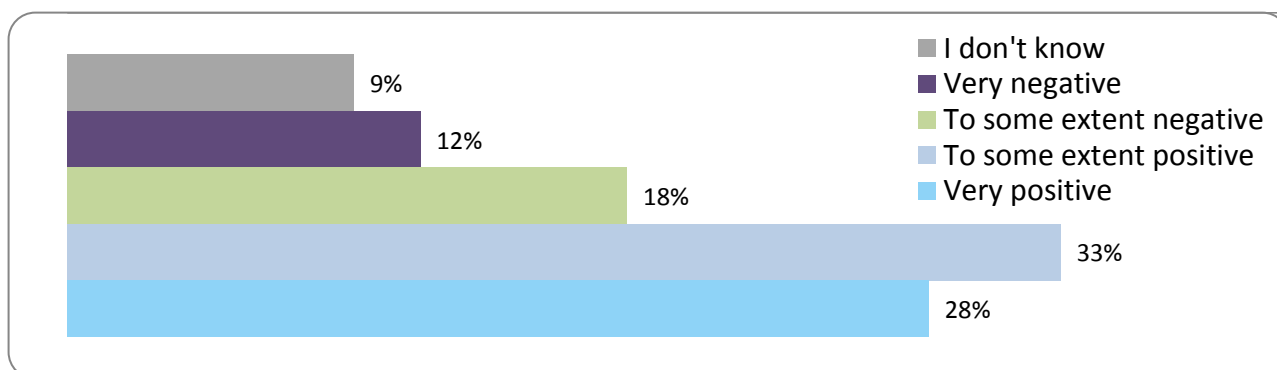


Figure 35: Summary of opportunities, caveats and concerns regarding genome editing in animals to cure human disease

#### 4.2.3 Using genetic technologies in animals for food

Participants in the dialogue in Edinburgh were not convinced of the need for society to use genetic technology to develop a faster growing variety of Atlantic salmon. This reluctance chimes with the findings in the survey which shows that only 18% of the population see the use of genetic technologies in animals to increase the efficiency of food production as 'very positive' and 32% see it as 'to some extent positive' (51% in total). The research shows that there is more support for the use of genetic technologies in animals to prevent or cure disease than for the production of food and that science still needs to engage with poor perceptions of genetic technologies applied to food production in society. There is one notable exception to this view demonstrated amongst 18-34 year olds. 28% of respondents to the survey in this age group found this development 'very positive' and 33% 'to some extent positive' (61% in total) see figure 36), suggesting that increasing the efficiency and profitability of food production through genetic technologies is a concept with wider support amongst under 34 year olds compared with the 55+ age group (15% 'very positive'; 37% 'to some extent positive'; 51% total). The same statement was seen as 'very positive' in only 13% and 'to some extent positive' in 29% of 35-54 year olds (42% in total).

Figure 36: 18-34 year olds' response to increasing the efficiency of food production through genetic technologies



However, in discussions around the salmon case study there was recognition that the technique can be used for other purposes, which for some in the dialogue makes it a worthwhile investment,

*'Those same techniques can be used for other things. It's not 25 years of research only to have a bigger fish. Those techniques can then be applied to everything else. The techniques are transferable.'* (Edinburgh)

#### Non-essential solution

Although dialogue participants didn't reject the use of genetic technologies for this application as such, the majority view was that it should only be applied when there is a real need for society to embrace the development and when other options are proven to be less effective. As someone in round 2 of the dialogue in Edinburgh summed it up,

*'I do believe genetic study and research has a lot of good applications. The knowledge of how things come to be, how they exist, is very useful in itself. It's the application of that knowledge and how it's chosen to be applied in this case, I don't feel it's justified. We're not starving if we don't eat a salmon.'* (Edinburgh)

Views on alternative solutions included looking at the root issue of hunger in the world and advocating for a change of diet,

*'We are over eating, over spending, we're wasteful, we're not dealing with the current circumstance, but we're looking at alternatives.'* (Edinburgh)

*'Does the world need to eat salmon? If consumption of tilapia is better for the ecosystem why aren't we pushed towards behaviour change?'* (Edinburgh)

#### Concerns about impact of consumption on human health

Another important consideration underpinning the views of participants in the dialogue was the impact on human health of the consumption of genetically modified animal. Nevertheless, some held the view that genetically modified animals for food may be better for human health than conventionally bred animals due to the extensive use of additives and antibiotics (see section 3.5 on regulation).

#### Lack of clear information drives suspicion of corporate greed

Clarity of information was seen as vitally important in the case of using genetic technologies on animals for food as indeed with the other applications discussed in the dialogue sessions. One participant said they still felt fearful in round 2 of the dialogue,

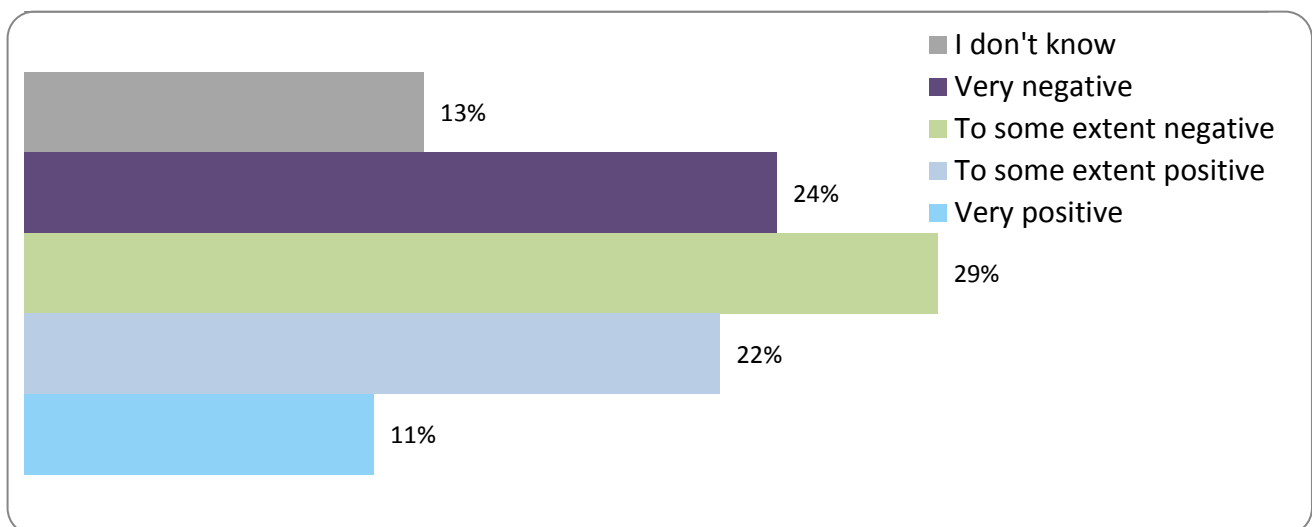
*'Just because of the unknown, and finding out that this is going on in Canada and we don't know anything about it.'* (Edinburgh)

The lack of information about the real need for the genetically modified salmon led to a view that this application is overly driven by profit rather than common good. This was a wide-spread belief amongst dialogue participants as typified in this comment,

*'Scientific endeavour should be for the greater good if you've got morals and ethics, and not for profit.'* (Edinburgh)

Although the case study was framed as an application to reduce the negative impact of fish farms, participants focused their discussions primarily around the societal need for it and indicated across the groups that profitability should not be a primary consideration for introducing food produced through the application of genetic technologies. This view was validated in the survey where respondents were asked to what extent using genetic technologies in animals for food is a positive or negative development for society when this is done to increase profitability. 24% of the population saw this as a 'very negative' development and 29% as 'to some extent negative' development for society, (54% in total, figure 37).

Figure 37: To what extent is using genetic technologies in animals for food is a positive or negative development for society when this is done to increase profitability (e.g. genome edited cattle that grow larger)



As with improving the efficiency of food production, we see a difference in the responses in the 18-34 age segment here with 18% of respondents in this age group rating increasing profitability as 'very positive' and 25% 'to some extent positive' for society compared to 10% and 19% in the 35-54 segment, and 7% and 23% in the 55+ age segment, respectively.

#### 4.2.4 Other uses of genetic technologies in animals

In the survey three other uses of genetic technologies in animals were tested:

- Using genome editing to prevent disease in livestock (e.g. genome edited pigs that are resistant to African Swine Fever)
- Using genome editing in animals as a way of removing invasive species (e.g. the Asian hornet in the UK)
- Using genome editing in animals as a way of preventing crop damage (e.g. using genetically modified moths to limit the growth in pest populations that feed on crops).

There was substantial support for the use of genome editing in animals to prevent disease in livestock with 28% of respondents indicating they see it as a 'very positive' development for society and 43% 'to some extent positive' (70% in total, figure 38). 23% of respondents said the use of genome editing in animals to remove invasive species is a 'very positive' development for society and 37% said it is 'to some extent positive' (59% in total, figure 39), whereas the use of genome editing in animals to prevent crop damage scored lower (18% 'very positive'; 38% 'to some extent positive'; 56% in total). These specific examples were not discussed in the dialogue sessions.

Figure 38: The extent to which using genetic technologies in animals for food is a positive or negative development for society when this is done to prevent disease

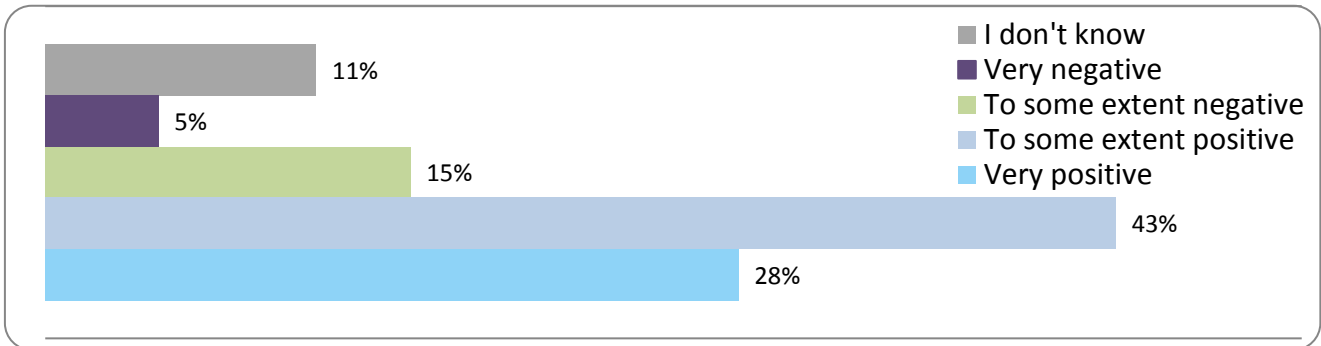
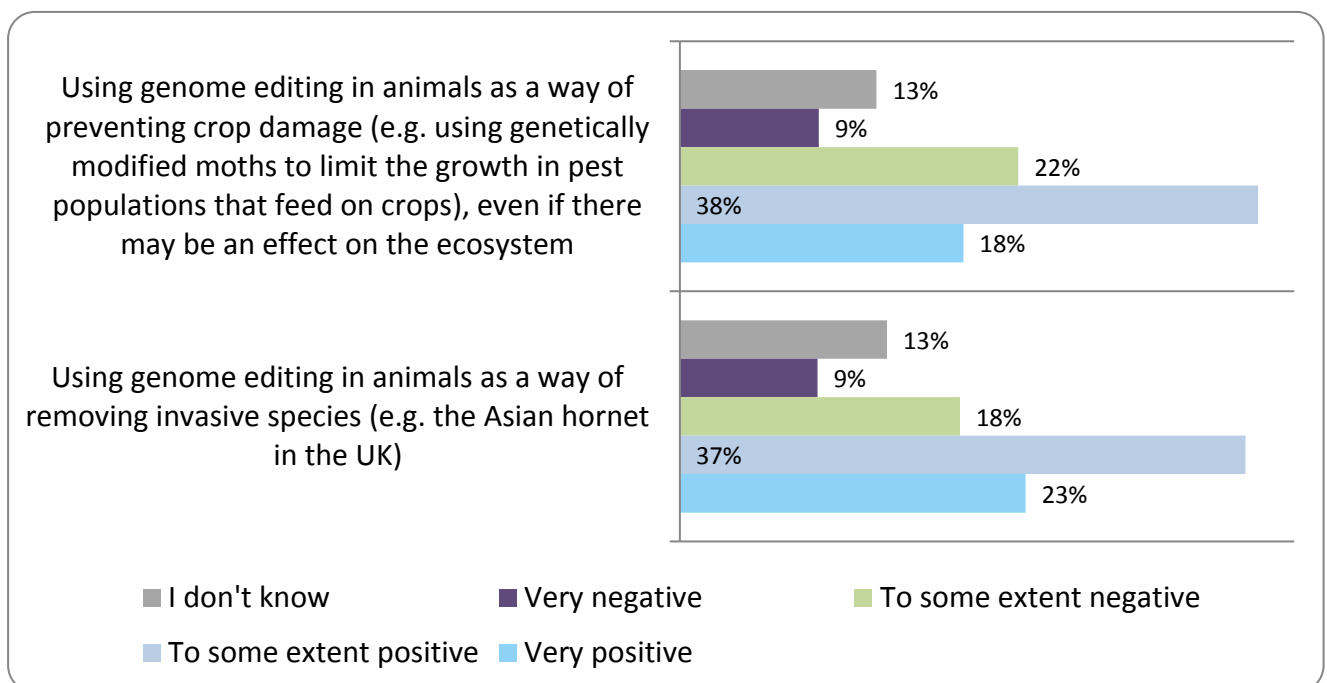


Figure 39: The extent to which using genetic technologies in animals for preventing crop damages/ removing invasive species are a positive or negative development for society



The summary of main findings for genetic technologies applied to animals is found in figure 40.

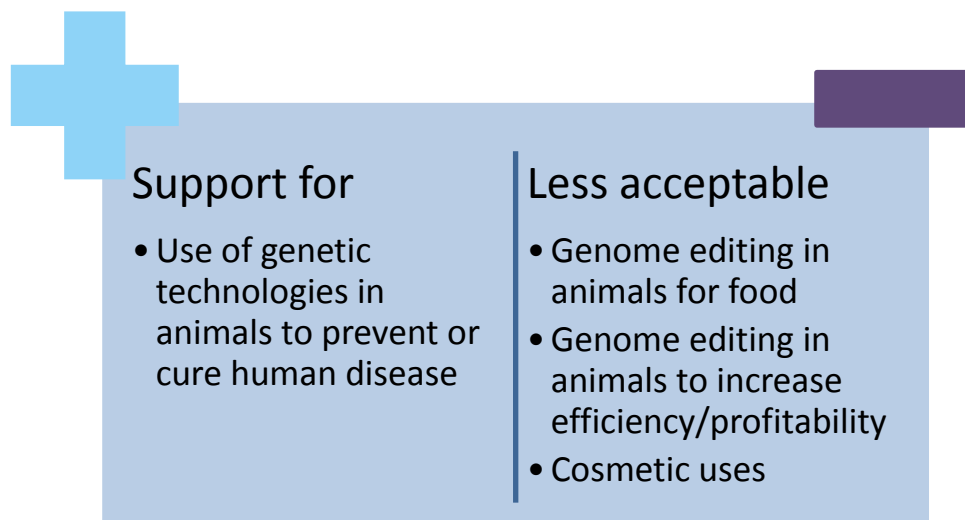


Figure 40: Summary of the support for/less acceptable uses of genetic technologies in animals

### 4.3 Plant applications

Participants in Norwich explored three uses of genetic technologies in plants and micro-organisms:

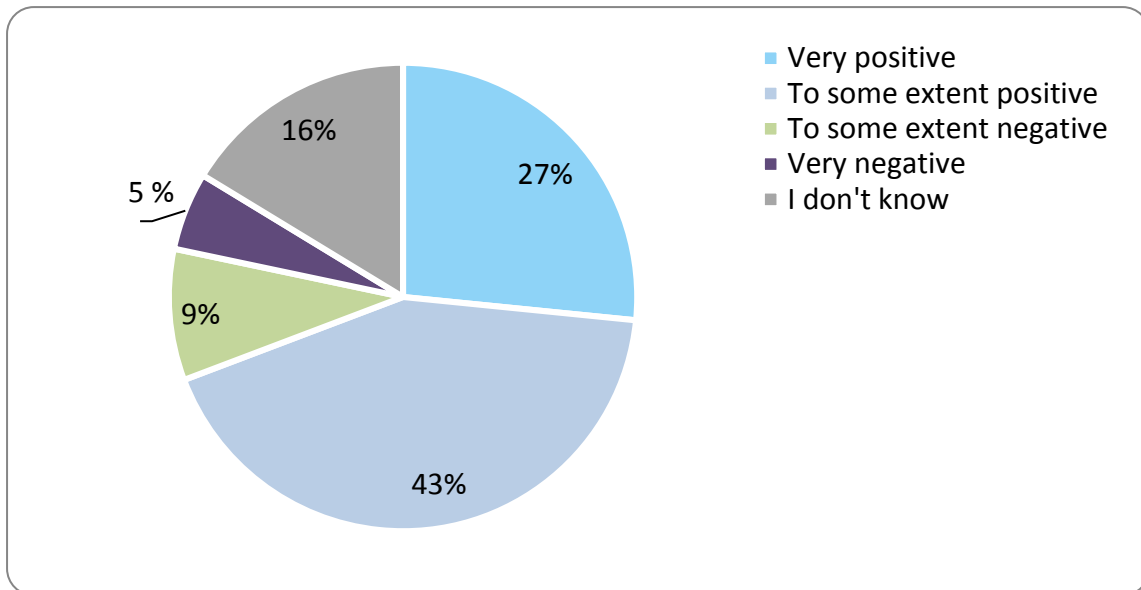
- Using genetic technologies to develop new medicines more cheaply, with the use of tobacco plants to produce biopharmaceuticals for treatment of, for example, Ebola and HIV
- Using genetic technologies to prevent fungal disease in plants, which explored the example of a blight resistant potato crops
- Using genetic technologies to reduce vitamin A deficiency, which focused on the Golden Rice example.



#### 4.3.1 Use of genetic technologies in plants for the development of medicines

In the survey we found high levels of support for the use of genetic technologies in plants for the cost-effective development of medicines (figure 41). 27% indicated to see this as a 'very positive' development for society and 43% 'to some extent positive' (69% in total).

Figure 41: To what extent do you consider it to be positive or negative for society to use genetic technologies in plants for the cost-effective development of medicines (e.g. using genome editing to modify tobacco plants to produce bio-pharmaceuticals)?



### Hopeful development

In line with the survey findings, the majority of participants in the dialogue sessions responded positively to the use of genetic technologies in tobacco plants to produce biopharmaceuticals. They discussed the use of tobacco plants to produce drugs for the treatment of Ebola and HIV,

*'I think despite our differences, all of us, in our roles, felt that it was the best way forward in our case study. With a bit more knowledge about it, it helped us to say yeah, that it's probably a bit safer than some of the stuff we're currently given, or eat; which is scary, but an interesting learning point.'* (Norwich)

Participants felt it was a hopeful development as big global issues such as Ebola and HIV need to be addressed quickly to help save lives,

*'We considered it as the safest and quickest way to save lives in this case.'* (Norwich)

*'I think the end goal is to save lives. To save the planet, that's the focus. Along the way we're going to veer off, but we need to have one goal at the end of it, and I think we all agree on that. For our children, our grandchildren, that's what we want.'* (Norwich)

A particular hope in this context was that the process of genome editing will result in medicines with fewer side-effects than conventional medicines. As a participant in one of the groups in round 1 of the dialogue said,

*'One of my hopes is that, if plants are used for medicine then there wouldn't be any symptoms when it cures diseases, unlike prescription drugs.'* (Norwich)

As described in section 2.4 participants demonstrated an appreciation of the process applied to the tobacco plant as they saw it as an opportunity for more equal availability of drugs as a consequence

of price decreases. From their point of view access to some drugs is limited due to the cost, one of the groups expressed this sentiment in relation to cancer treatment,

*'I'm hoping you can use GM plants to make cancer drugs. This will decrease the price, so it's available to all. Currently NICE develop a lovely new cancer drug and we can't afford it.'* (Norwich)

The case study group expressed their sense of hope and positivity in the poster exercise (figure 42) by the use of words and phrases such as, *'We're here to help'*, *'Here's looking at a better world'* and *'Explore the benefits of genetic technologies to benefit society'*.

And in the group's advice to an imaginary meeting (see section 1.4.5 for an explanation of the methodology) of stakeholders discussing considerations around taking this use of genetic technologies further they said,

*'Explore genetic technologies to benefit society, you'll be amazed where we can take you.'* (Norwich)

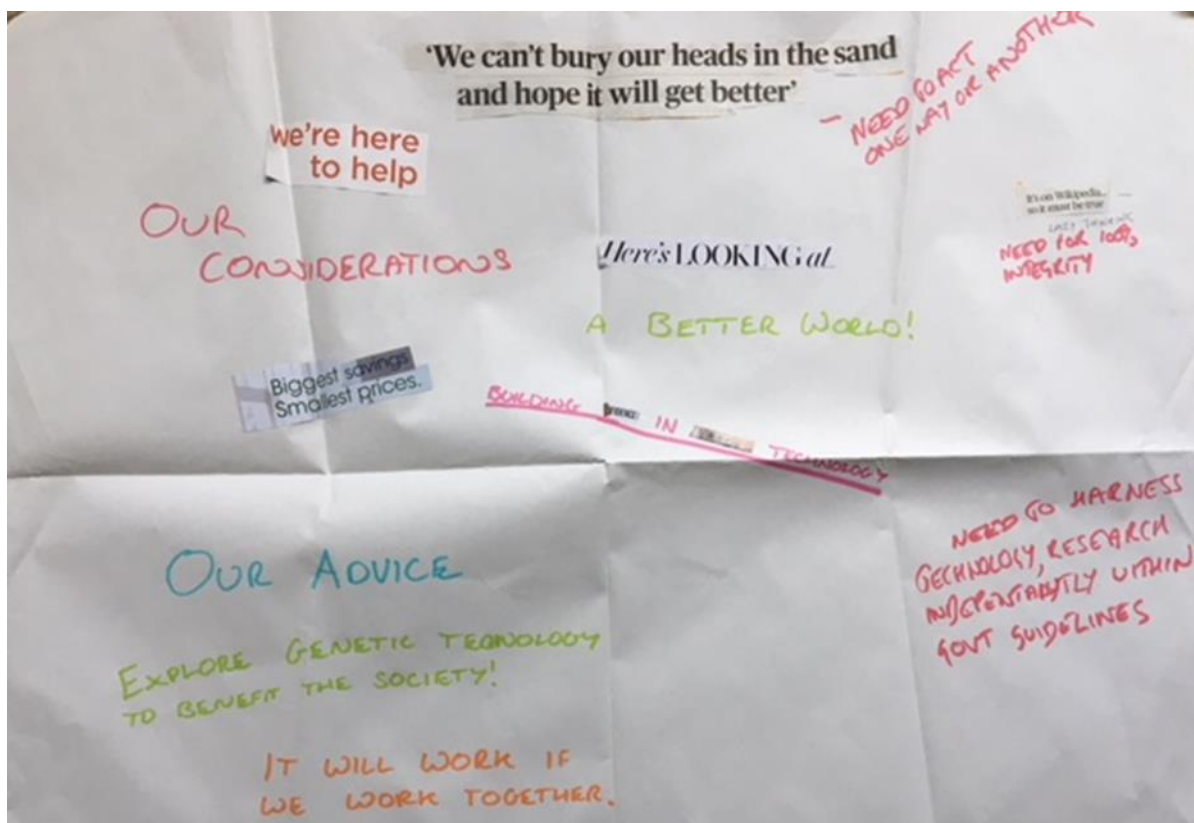


Figure 42: Visuals created by Norwich participants on using genetic technologies for the cost-effective development of medicines

### Caveats

Underpinning participants' reaction to the use of genetic technologies to develop new medicines more cheaply was a strong sense that there is a need for excellent international collaboration for this to be a positive development for society,

*'It will work if we work together.'* (Norwich)



There was an understanding and appreciation of the fact that the use of genetic technologies in plants to produce medicine is potentially more cost effective,

*'Yes, because it can be sped up, it takes less time so it can be more cost effective.'* (Norwich)

With a view that this might reduce the strain on current health budgets,

*'If we act now, we get money now.'* (Norwich)

Participants' main concern in this case study was the potential ecological impact of contamination of other crops. The fear around cross contamination was mostly based on the prospect of creating unplanned, unexpected new species that could have unforeseen consequences, in the words of one participant,

*'The land of unintended consequences.'* (Norwich)

There was also a concern that working at such a pace to use the technologies to create drugs as a treatment for patients might result in short cuts being taken which could affect the quality of the treatment, or even cause harm. As one participant stressed,

*'It would be important to make sure that it was all being done ethically and that corners might have been cut, but that they haven't done any damage by being cut.'* (Norwich)

They discussed that a prerequisite for developing genetic technologies in plants for some participants was the need to ensure enclosed spaces are used to prevent cross contamination between plants and species.

As in all previous case studies participants felt strongly that there is a need for education and effective information about the opportunities offered by genetic technologies to produce cheaper medicines. We see this reflected in the poster as *'Share information to dispel myths'* and *'Education and lifelong learning'* (figure 44).

The opportunities, caveats and concerns that dialogue participants expressed in relation to developing new medicines more cheaply are summarised in figure 43.

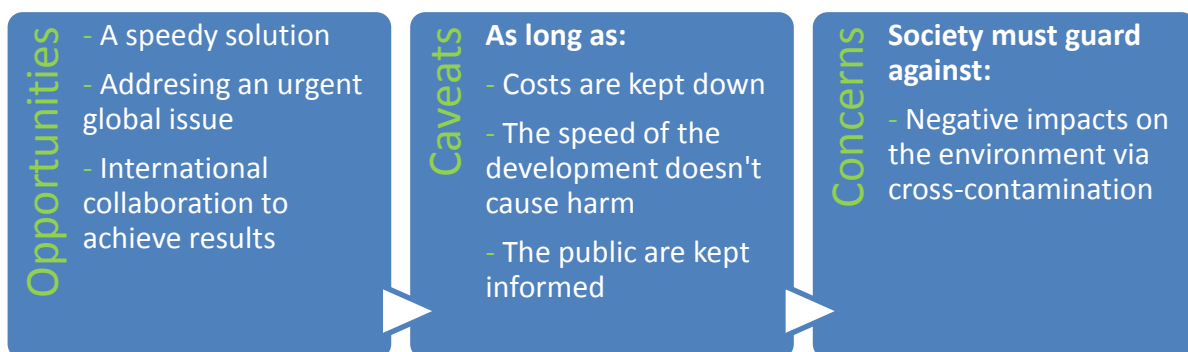


Figure 43: Summary of opportunities, caveats and concerns regarding genetic technologies in plants to develop cheaper medicines.

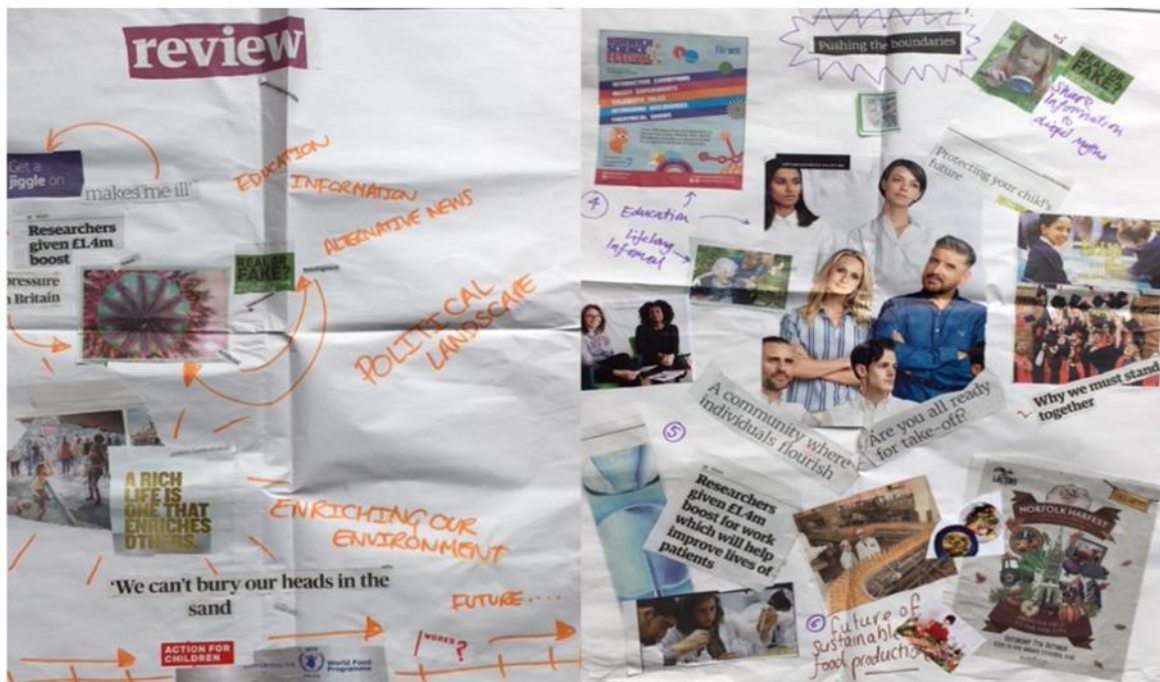


Figure 44: Visuals created by Norwich participants on preventing crop damage

#### 4.3.2 Use of genetic technologies in plants for food to prevent crop damage

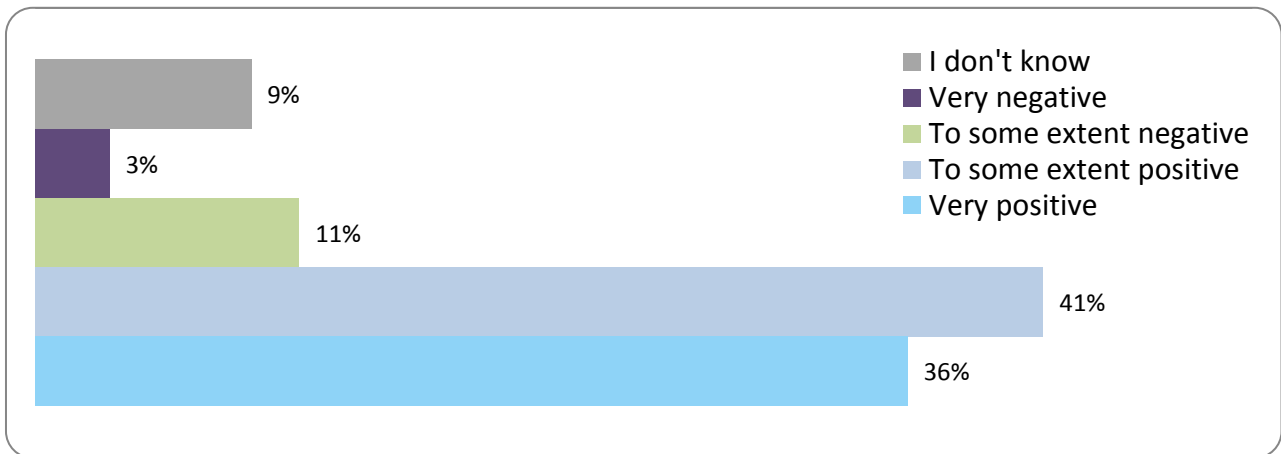
In the dialogue one of the groups in Norwich discussed the use of genome editing to reduce the risk of fungal disease in plants. They discussed the blight resistant Desiree potato. Participants responded positively to the case study and saw it as a good addition to a range of solutions to help achieve a sustainable food system and feed a growing world population. In the poster exercise (figure 44) they used phrases such as *'Why we must stand together'* and *'A rich life enriches others.'* They said that it was hopeful to see news about science being awarded grants: *'Researchers given 1.4m boost for their work which will help improve lives of patients.'* Even though this news clipping relates to patients, for participants it was an expression of their trust in science.

This view was reflected in the survey (figure 45), where 41% of the respondents indicated that the use of genetic technologies in plants for food to prevent crop damage is 'to some extent positive' for society and 36% responded that in their view it is 'very positive' (77% in total).

#### Caveats

It is worth noting here that respondents to the survey were asked about their views on using genetic technologies in animals as a way of preventing crop damage (e.g. genetically modified moths to limit the growth in pest populations that feed on crops). In their responses we found a lower acceptance for this than applying genetic technologies to plants for the same purpose with 18% of the population selecting 'very positive' as their response and 38% describing the development as 'to some extent positive' (56% in total).

Figure 45: The extent to which it is positive or negative for society to use genetic technologies to produce plants for food when this is done to prevent crop damage



As in other case studies, one of the main caveats was the need to dispel myths about genetic technologies in society. This was illustrated in the poster in the use of a press cutting of the words *'Real or fake?'*, reflecting a discussion about which information is trustworthy and the need for long education about the advances in genetic and other technologies. There was a view that there is a role for scientists and professional networks to provide objective information about the application and the context in which technologies are developed,

*'What I was basically trying to say is that their role is to bring more awareness and knowledge of the crops, and in terms of alternatives, the pros and cons of each alternative.'* (Norwich)

*'So it needs to be the positive side of it that needs to be promoted.'* (Norwich)

*'I'd say get out to the public. I'd say to start with schools, educate, and that's not just because I'm a teacher. I think educate the public on what are the benefits. Start with history. 1m people died in the potato famine in Ireland, and 2m emigrated, do we want to see that again?'* (Norwich)

And some participants held the view that it's about all layers of society to ensure there is a pipeline of young people interested in working in the industry,

*'I'd like to go one step further than educating in schools. I actually think we should be increasing the funding for university links to the private sector. Children go through schools, and then they get to 18 and go to university, this is not going to stop, this GM research, and actually, young people choosing to do that should have the choice and the ability to go and study that and work in that sector, and we should improve their chances of doing so.'* (Norwich)

The main concern of participants was related to the safety of the application, particularly in regards to potential contamination of other crops. Questions included whether contamination of other crops would be reversible. This concern was validated in the survey, in which respondents were asked to indicate to what extent they agreed that genome edited plants should be cultivated in such a way as to prevent cross-contamination with related plants that have not undergone genome editing. There was strong support for this notion with 42% of respondents saying they agreed very strongly and 30% that they agreed to some extent (72% in total).

The opportunities, caveat and concerns that participants expressed in the discussion of genetic modification of Desiree potatoes to provide resistance to late blight are summarised in figure 46.

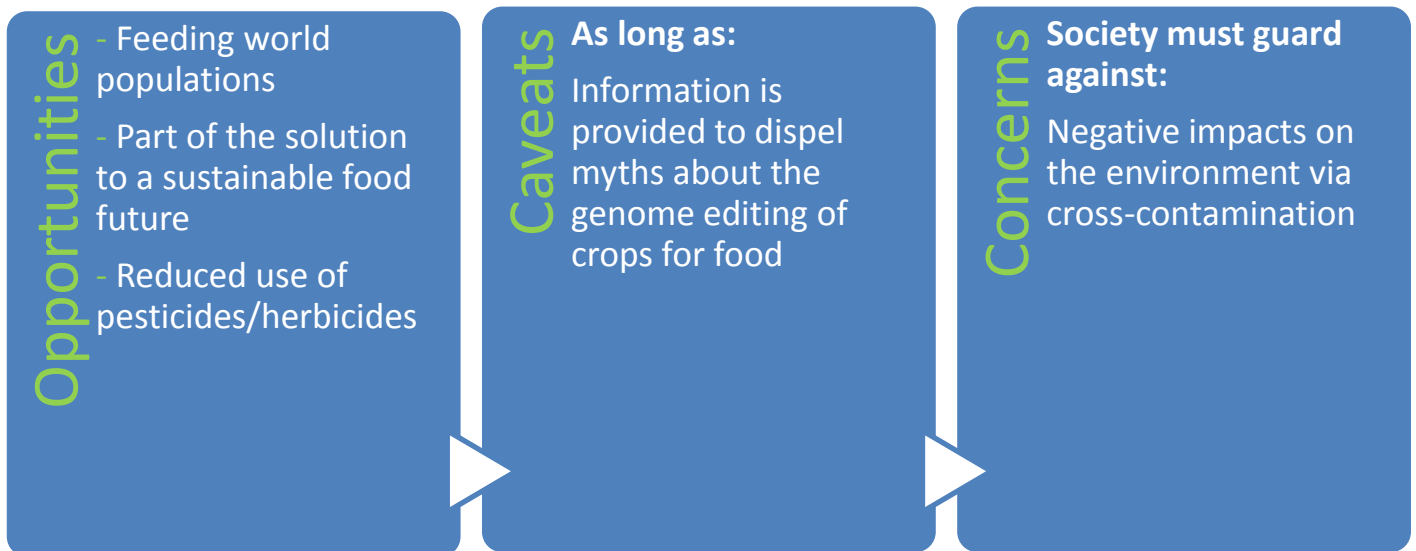


Figure 46: Summary of opportunities, caveats and concerns regarding using genetic technologies in plants to prevent crop damage

#### 4.3.3 Use of genetic technologies to supplement poor diets

Participants, having read the Vitamin A case study, felt very positively towards the project as an opportunity to use science to deal with hunger in the world,

*'Well we think Golden Rice could be the solution to feeding the world. In the mid-century we're predicted to have a massive population explosion. [...]So we need to ramp up our food production to deal with the increase.'* (Norwich)

*'There's obviously a lot to be done, testing of the science and regulation and so on, but we'd like to use all the magic to address all the suspicion there is.'* (Norwich)

Other considerations they reflected on are health benefits, a faster way of addressing the problem, more cost-efficient, and more environmentally friendly than meat production. This was illustrated in the poster exercise with both groups including pictures of (processed) meat and the comments *'freshness'* and *'the cost of meat versus grains and legumes'* and the following comment about the picture of a child and the words *'good for health'* (figure 47),

*'Yes ok we've got a little bit of a mix here, we've covered a lot of the issues but we're sort of putting it into a positive light so we've got healthy eating, health, happiness as well.'* (Norwich)



Figure 47: Visuals created by Norwich participants on using genetic technologies to supplement dietary insufficiencies

### Caveats

Participants discussed that an application like this challenges the UK public to take a much more global perspective,

*‘There’s an opportunity for us to continue helping each other in developing the golden rice into the world food programme to feed people that needed it the most. It’s all about just looking after each other really and just being aware of not just what goes on in our own country.’ (Norwich)*

Hence words in the poster such as *‘We’re here to help’*.

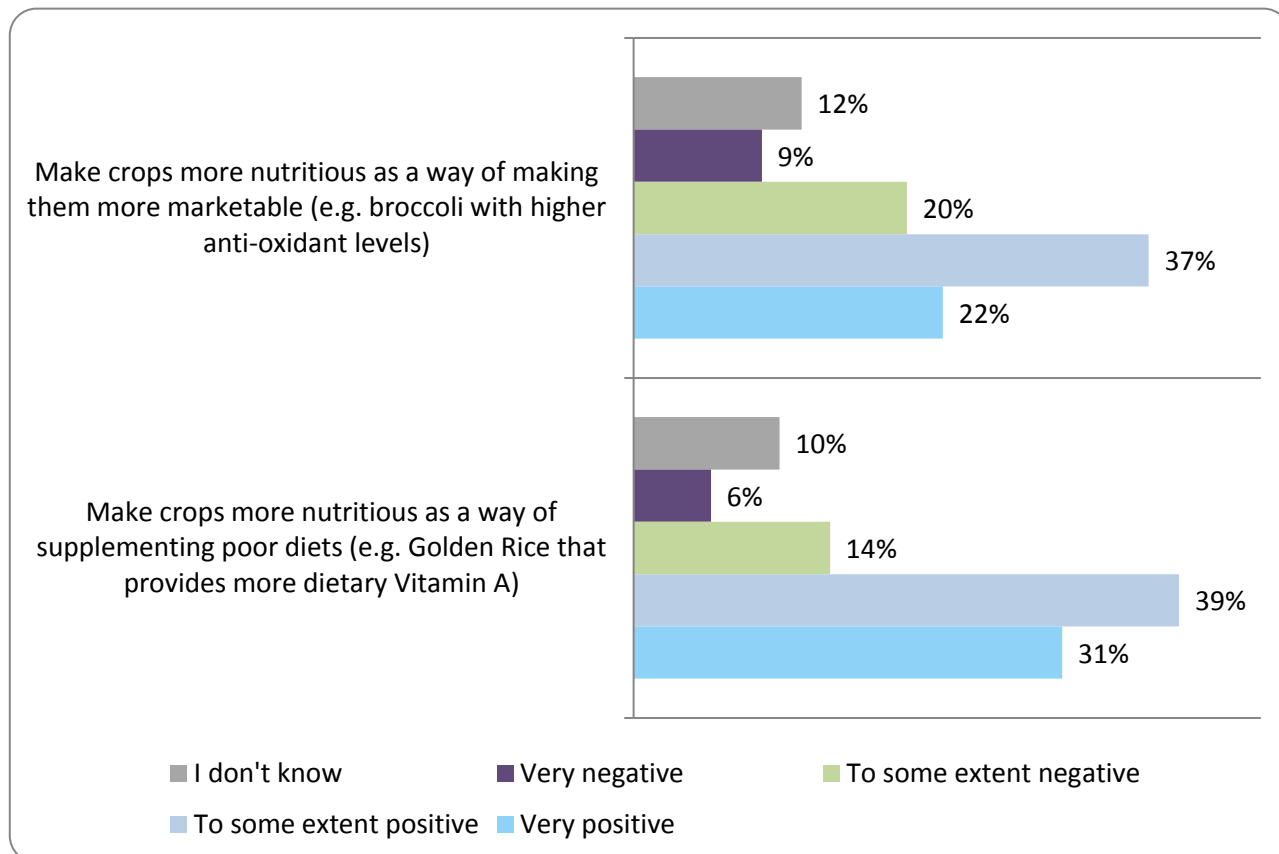
As in other case studies effective testing and regulation was a prerequisite for acceptability as was the provision of clear information about the application. One participant explained how he was surprised to learn that the consumption of GM food is as safe as conventional food,

*‘Well I mean this was news to me, one of the quotes. [...] I’m taking it of Professor Jonathan Jones who’s spent 30 years researching the risks into this topic. It says GM food and crops are as safe as non GM food and crops which isn’t to say they’re completely safe but they’re as safe and that’s news to me, even after, you know, this is the second session focussed on this specific issue I mean that’s what I would be putting a big flashing light everywhere. These are the risks of traditional foods and these are the risks of GM foods, they’re pretty similar.’ (Norwich)*

The positive attitude to the Golden Rice case study was validated in the national survey. 39% of respondents answered ‘to some extent positive’ when asked about the extent they find the use of genetic technologies in plants for food to make crops more nutritious as a way of supplementing poor diets a positive development for society, with 31% responding by selecting ‘very positive’ (70% in total). We found a slightly lower acceptance for the use of genetic technologies to make plants more nutritious as a way of making them more marketable with 22% responding by selecting the

'very positive' option and 37% selecting, 'to some extent positive' (59% in total). This demonstrates that the survey testing the views of the UK population echoes the views of dialogue participants who were somewhat less accepting of genetic technologies in all applications when commercial considerations come in to the picture. Figure 48 summarises the survey findings that relate to these questions.

Figure 48: The extent to which it is positive or negative for society to use genetic technologies to produce plants **for food** when this is done to:



Participant views on opportunities, caveats and concerns in relation to the genetic modification of rice to provide more dietary Vitamin A are summarised in figure 49.

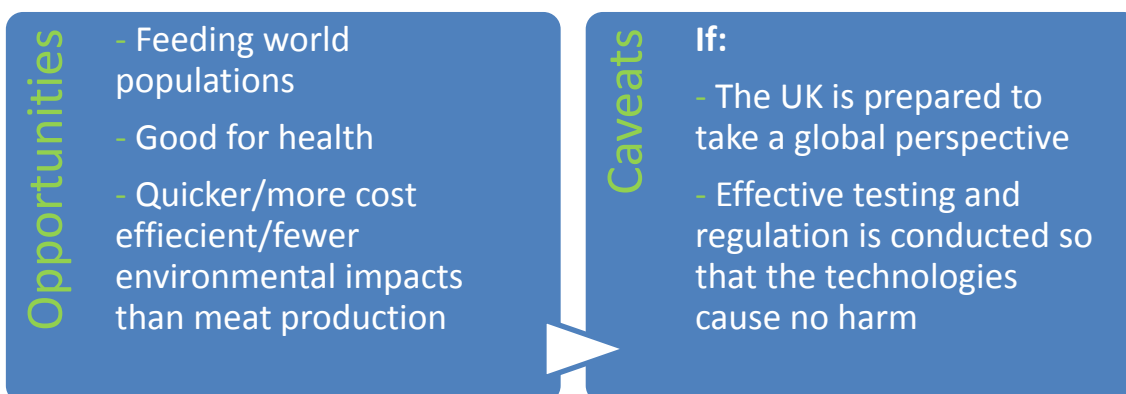


Figure 49: Summary of opportunities and caveats regarding genetic modification of rice to provide more dietary Vitamin A

#### 4.3.4 Use of genetic technologies in plants for cosmetic reasons

In line with findings about the acceptability of the use of genetic technologies in humans and animals for cosmetic reasons the survey shows that there is minimal support for the use of genetic technologies for cosmetic reasons in plants, for example to make vegetables look more attractive to the consumer. As already seen in section 3.3 on individual welfare, 51% of the respondents strongly disagree that this is a positive development for society and 17% disagree to some extent (68% in total).

This chimed with discussion held in the public dialogue. As one participant said,

*‘Why are we spending time considering the appearance of fruit, veg and plants when there are more practical purposes to be considered like medical conditions?’ (Norwich)*

The use of genetic technologies to prevent or cure disease took priority over other applications in all discussions. In the plant and micro-organism workshops in Norwich this attitude transpired in discussions about all three case studies. There was support for increasing the nutritional value of food and the production of cheaper medicine both from the perspective that they improve human health and the case of preventing crop damage was mainly related to the opportunity participants saw for this application as part of a package of solutions to lead to a more sustainable food future.

The applications of genetic technologies to plants which are more or less supported by participants are summarised in figure 50.

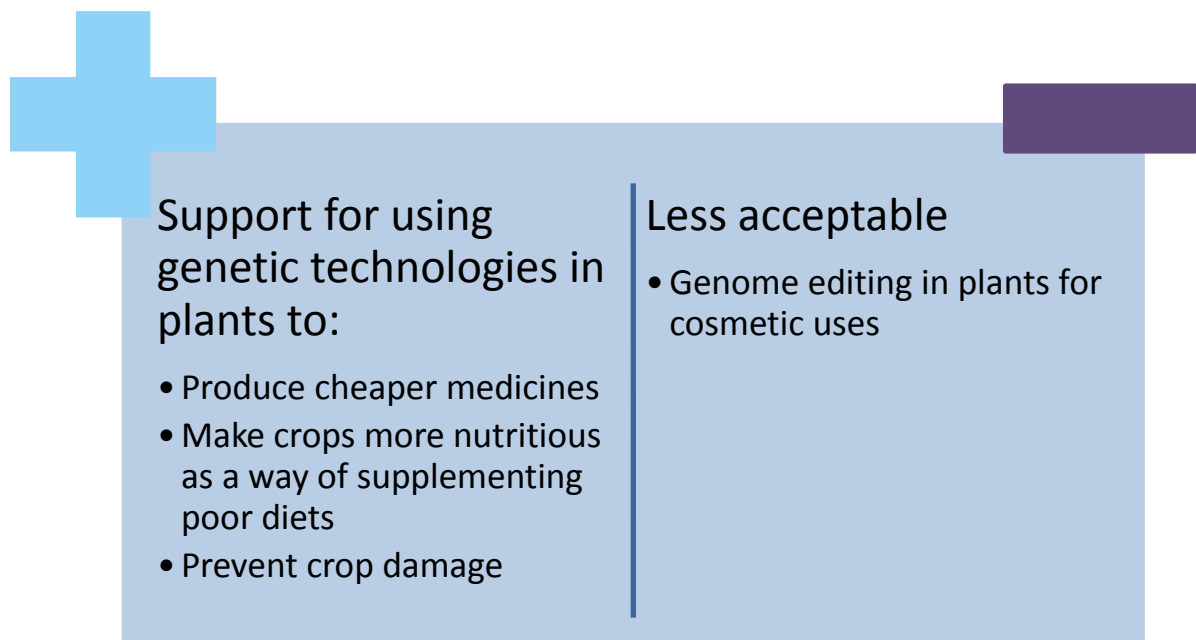


Figure 50: Summary of the support for/less acceptable developments in plant applications

# 5. Trusted actors

## Chapter 5 summary

Workshop participants discussed who they trusted to develop, to advise on and to regulate genetic technologies during the afternoon of the round 2 workshops. An analysis of the findings from these discussions is set out in this chapter.

It is worth introducing this chapter by saying that many participants expressed a general unwillingness to trust any 'authority figures', be they government, academia, business or NGOs. Participants could cite specific examples for each of the actors under discussion where they felt they had been shown to act in a way that was not for the public good.

In all locations university academics and researchers were seen as the most trusted actors to work on/develop uses for genetic technologies. University academics were most trusted as well to advise and inform on genetic technologies, followed by professional networks (for London participants) and charities, trusts and foundations (for participants in Norwich and Edinburgh). In relation to information and advice the survey findings were somewhat different with the majority seeing university academics, scientists and researchers as most likely to provide trustworthy information and advice on genetic technologies, followed by businesses working or funding research on genetic technologies and government bodies/policymakers.

The reasons for these rankings are explored in the chapter and summarised below.

### More trusted when the actor:

- Is the source of unfiltered knowledge
- Demonstrates impartiality and independence
- Has academic rigour and works within an ethical framework
- Has dedicated their life to science not profit
- Draws on intelligence, years of experience and specialist knowledge
- Works for the global good and is connected to real world challenges.

### Less trusted when the actor:

- Is motivated by profit
- Demonstrates a lack of transparent process or scrutiny
- Is perceived to be less well regulated
- Can be influenced by where the funding for the research comes from
- Is slow, or does not act in the public interest.

The chapter closes with an analysis of the consensus reached in all dialogue groups in each location that some form of multi-disciplinary panel or commission should regulate genetic technologies. A variety of ways of achieving this were suggested with the principle point being made that genetic technologies will affect everyone's lives and therefore regulation should draw on everyone's views. They felt the panel proposed should include all stakeholders including the general public as informed citizens.

The issue of including the public is summed up well by this dialogue participant:





Workshop participants discussed who they trusted to develop, to advise on and to regulate genetic technologies during the afternoon of the second workshop.

They were asked to individually rank who they trusted most and trusted least to develop genetic technologies and then who they trusted most and trusted least to advise on genetic technologies. The focus of the discussion was on eliciting the reasons for trust or lack of trust.

Participants were given the following actors and definitions to discuss: who is most trusted to work on/develop genetic technologies:<sup>7</sup>

## Businesses working in genetic technology

Develop & deliver products or services for a profit



## Privately funded academics/scientists/ researchers

Funded by private & public funding, using the scientific method to add knowledge & insight to our common understanding



## Charities/ Trusts & Foundations

Delivering a public benefit/ championing a particular cause



## University academics/scientists/ researchers

Using the scientific method to add knowledge & insight to our common understanding

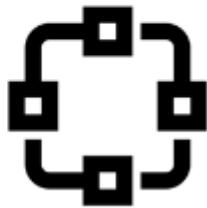


For advising and informing about genetic technologies, all the actors above were ranked and discussed, in addition to the following:

<sup>7</sup> In London, the first R2 workshop, participants also discussed patent holders and non-governmental organisations: we found that participants quite reasonably made little distinction between businesses and patent holders and they found NGOs too amorphous to discuss, thus this was broken down into Charities & Foundations and Campaigning organisations for the Norwich and Edinburgh workshops.

## Professional/ specialist Regulatory networks organisations

Providing advice, support & a platform for members whilst advising on & engaging society in areas of expertise

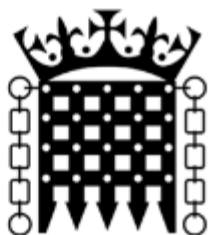


Ensuring work is conducted to the highest professional & ethical standards as well as complying with all relevant UK & global legislation



## Government bodies/ policy makers

The implementation of government policy in the UK



## Campaigning organisations



There was widespread distrust amongst dialogue participants of any authority figure. This was based on experiences of: government being slow to act on the harms of tobacco; business for rapacious practices such as hiking up the price of an HIV medicine; charities for pressurised fund raising and misuse of donations; campaign groups for pushing skewed evidence; privately funded researchers, for misleading research such as MMR; and universities for increasingly acting like businesses,

*'So many organisations over the last ten or twenty years have been shown not to be trustworthy; whether it's banks, politicians, so that you look at it and you think 'what the hell?' How do you pick one from another? I think standards have fallen generally.'* (London)

*'For me, it's almost, who's got the least agenda? Who can be the most objective, as opposed to peddling whatever angle they want to peddle?'* (London)

However, there were clear and significantly consistent preferences across the locations for who was most and least trusted. This section looks at who they are and the reasons given by participants.

## 5.1 Most trusted to work on/develop uses for genetic technologies

In all locations university academics and researchers were seen as the most trusted actors to work on/develop uses for genetic technologies, followed by professional networks in London and Charities, trusts and foundations in Norwich and Edinburgh. Here we set out the reasons people gave for investing trust in these actors.

### 5.1.1 Reasons to trust university academics and researchers

#### Impartiality and independence

Unlike other actors, such as business which was seen as being profit-driven, or charities and campaigning organisations sometimes seen as focused on a single issue, universities were seen as having greater impartiality. This was derived from the sense that their academics had greater freedom to pursue good science for the sake of a better society,



*'Their main motivation is pursuing knowledge and research and so that's why I had them as being the most trusted.'* (Norwich)

*'There was an independent, sort of, about academic research that you don't get in the areas that are more privately funded.'* (Norwich)

#### Academic rigour and working within an ethics framework

All participants recognised that universities are governed by processes such as ethics committees and peer reviews and saw that as strong evidence that the work they do is carefully considered and for the public good,

*'They tend to be driven by ethics boards so anything, research that they do will probably go through stringent tests to see that it's ethical or vital or valid.'* (Edinburgh)

*'You have peer reviews, there's lots of things that have to go into this for it actually to be passed so it has its own set of regulations beneath of set of regulations that would be required over anything else.'* (Edinburgh)

#### A life dedicated to science, not profit

There was a strong, commonly held view that university scientists and academics were motivated by a love of science and the good it can bring to the world, rather than being motivated by monetary gain,

*'I would trust them the most because I would say maybe science, and research, is kind of their life, and I would trust them, that they would be prepared to dedicate life, or their whole work, to one project, rather than to some other organisations who have not got this life.'* (London)

*'As the wife of an academic, they don't get paid that much. They're not doing it for massive financial gain. It's a vocation, it's a love. You wouldn't do it for any other reason.'* (Norwich)

### Intelligence and years of experience

Trust in academics was also rooted in the sense that they committed years of their life to the study of a particular strand of science and to progress in academia they had to prove the extent and depth of their intellect throughout their careers and have a reputation to maintain,

*'I think it's that word 'academics'. You put your faith into knowledge, and you tend to think someone who's clever is the person to follow.'* (London)

*'They also build themselves on reputation as well; if you don't have a good reputation, they can't get [progress].'* (Norwich)

This finding is supported by the answers to a related question on the sources of information and advice on genetic technologies where 43% of the population ranked university academics, scientists and researchers as the most trustworthy.

### The benefit of young minds

Some participants pointed to the advantage of universities being full of young people, year after year, who bring fresh perspectives and news ways of thinking into academia,

*'With universities you're getting younger, fresher minds coming with different perspectives than maybe, you know, the older generation have so they might be thinking more ethically anyway.'* (Edinburgh)

Some caveats to the trustworthiness of universities were raised. Whilst they didn't mean that people did not trust universities to develop technology, their reservations are worth noting. The 'businessification' of universities was noted by a few participants,

*'I think individuals in universities doing research have probably got all the right reasons, however universities in themselves have become big business, and they need to attract money and they need to attract funding to do projects.'* (Norwich)

Others felt that scientists could become swept away by the potential of their scientific discovery or become overly concerned with burnishing their reputation which could conflict with developing something for the common good,

*'The scientists, some of them are so gung ho in this that they'll just kind of blank out other ideas and just get tunnel vision about what must change.'* (Edinburgh)

*'The end goal might be we want to create this amazing research so that we can win this scientific award and then they want to go up in the rankings.'* (Edinburgh)

### 5.1.2 Reasons to trust charities, trusts & foundations

For the good of the world

Those who ranked charities as their most trusted actor to develop genetic technologies pointed to their clear and unequivocal agenda for good. There was a clear sense that, like universities, they are not driven by profit, but are working towards an ethical or moral goal,



*'Their sole gain is going to be for the benefit of the greater good, not for a bank balance.'* (Norwich)

*'They have an agenda, but the British Heart Foundation, you know their agenda. They want to prolong and improve the quality of life of people who have heart problems.'* (London)

Connected to the real world

Several participants talked about trusting charities because of their 'in the field' knowledge of the issues facing the world, be that the impact of climate change or malnutrition in developing countries, or treating people with diseases such as cancer in this country,

*'They're kind of in the real world a bit more, a bit more connected. I'm not saying that academics aren't. I wasn't thinking of big charity organisations like Oxfam, I was thinking of the more specific ones.'* (Norwich)

The standards of governance and transparency

For some participants, the standards that govern charities and a culture of transparency were seen as further evidence that their work is robust and can be trusted,

*'I was thinking that maybe with charities the regulation is stricter so charities are governed by OSCR and you have to fulfil certain ethical requirements so that if you do the research it has to be approved in a certain way ethically before you get the funding or you can submit your accounts even to OSCR to get audited so you're very closely watched as a charity.'* (Edinburgh)

*'They have to report more stuff don't they? They have to report what they pay their people and where their money goes.'* (Norwich)

As with university academics and researchers, some participants also expressed reservations with charities developing genetic technology. Again, this did not denote mistrust, but rather caution. There was a sense that charities could be guilty of pursuing their goal so single-mindedly, that other issues might be overlooked or even suffer as a result,

*'Depending on the aims of said trust or foundation there could be vested interests as well, in terms of their funding or whatever.'* (Edinburgh)

*'I had the charities at number two because I thought that they had a vested interest in a cause so they were perhaps not as unbiased as an academic who are looking into the science of it not from a point of view which is to do with a specific cause or interest.'* (Norwich)

### 5.1.3 Reasons to trust professional specialist networks, business and privately funded academics

These actors received far fewer expressions of trust than charities and universities among dialogue participants, but the rationale for trust is worth noting.

#### Professional specialist networks

Some participants regarded professional specialist networks in the same light as university academics when it came to developing genetic technologies,

*'Because they're the specialists, so in my head, they know what they're doing, and they're professionals.'* (London)

*'They've had a lot of knowledge and they've done a lot to get to that position of working in that field, so for you to not trust them doesn't make sense to me, basically. I can't see any other hidden agenda.'* (London)

#### Privately funded academics

The word 'private' in its association with genetic technology, for a few participants, was analogous to the service you might expect from a private health service compared to the NHS: i.e. quicker and more efficient than public bodies,

*'The private aspect of things gives you your answers quicker than the normal NHS, and they're not the best to deal with the situation, but I think they're the best on diagnosis, they'll move fastest, and they always seem to be spot on.'* (London)

One participant also thought that privately funded academics might be more focused on their project because,

*'I think they've got more to lose if it all goes pear-shaped. I think they'd try harder.'* (Norwich)

#### Businesses

A handful of participants in both Norwich and Edinburgh challenged the generally held view about businesses not being trusted to develop genetic technologies. Reasons for supporting them included being focused on achieving their goals and being specialists in the field,

*'A business is more focused, and in my idea, more purist, because it's trying to achieve a certain thing. Obviously it's a business, and it has to make a profit, that's fair enough, but they have to justify earning that money in order to make that research, whereas a charity gets it given to them on a plate. They come by money a lot more easily.'* (Norwich)

*'If I want a car then I'd go to VW, so if I'm looking at genetic technology then I'd go to a genetic technology company, that just makes sense to me.'* (Edinburgh)

## 5.2 Least trusted to work on/develop uses for genetic technologies

Across all locations participants had least trust in businesses for the development of genetic technologies. Arguments included the view that ultimately businesses are driven by profit and not societal advancement as such and therefore they have a particular agenda. Privately funded researchers were less trusted than university researchers for similar reasons and NGOs/Charities/Campaigning organisations were equally seen as organisations that often follow a particular agenda and are not regulated by Government.

### 5.2.1 Reasons for lack of trust in business

#### The profit motive

Again and again, participants said that the main focus of businesses is to make profit for their employees and shareholders. This central motive was seen as incompatible with pursuing genetic technologies that were good for the whole world, not just a subset of profitable customers,



*'I don't know if making big profits and being ethical can ever come together.'* (Norwich)

*'It's a specific desired outcome that they want, and so research would be, in my opinion, quite biased towards what they want and what they can sell.'* (Norwich)

As discussions continued, the following reasons for discomfort with the profit motive emerged:

#### Refocus on something more profitable

Some participants worried that whilst a business might for a while work on a genetic technology that would be good for the wider world, if another, more profitable but less socially-good technology looked promising, the business would switch its resources to that,

*'They might get funding for genetic technologies to cure Ebola for example but then what happens when someone has more money that comes along to say, change the visual appearance of this plant? Would they then go onto doing that because it's more money?'* (Norwich)

#### Cut corners

Recent examples of large, seemingly respectable businesses acting dishonestly, such as VW and the emissions scandal, seem to have further undermined trust in businesses. There is a sense that corners will be cut, if it yields more profit,

*'Because that's their motivation, the money is their sole motivation. So you see with many companies they're willing to cut corners, do dodgy things and regardless of how big or multi-national they are behind closed doors we don't really know what's going on, whose hands they're shaking, what deals they're doing.'* (Norwich)

*'I think that they're profit based and that in general they could actually misrepresent or hide some detrimental aspects.'* (Edinburgh)

### Lack of data sharing

Many participants felt that genetic technologies, because they change the fundamental building blocks of life, should be shared for the greater good of the world, and not be kept under corporate lock and key to drive profits,

*'They've got the technology and they can control it. It's about this openness, and the sharing of the technology, and the limitations on the length of time somebody can have ownership of things like that.'* (Norwich)

### Regulation of business is more lax than academia and charities

The idea that businesses are less rigorously regulated than other sectors was widely felt by participants. This led to the belief that technologies could be developed that are based on data that is skewed and therefore dangerous,

*'I feel that in business regulation is a lot shiftier and you can buy your way into things and contracts and be bought which is not morally acceptable but it happens all the time so therefore anyone working in that whether they're scientists or not can be bought to make the data represent something that it's not, to say this is really safe and lots of people die having used it but they've got a commercial interest they've earned their ten million pounds so they don't care about the consequences.'* (Edinburgh)

### 5.2.2 Reasons for lack of trust in privately funded academics

#### Less scrutiny than universities

Most participants believed that privately funded academics worked to a different, less scrutinised set of standards than publicly funded academics and this undermined trust in the work that they did,



*'Because they don't necessarily need to operate within the same framework as university academics and researchers. They're working to a level of scrutiny- university academics work, I would say to a level of scrutiny- whereas privately funded people might not be.'* (London)

*'This privately funded seemed a bit woolly. Who's actually commissioning this research, who's funding it? Where's it coming from and why? Because it's private, in my head, it felt more shrouded in secrecy, which is therefore why I felt I was least able to trust it.'* (Norwich)

#### Influenced by who is funding it

With private funding, the motives of the person or organisation funding the research and the research outcome were bound up together in participants minds – they questioned why else they would fund research, and said that they would not fund it if it conflicted with their motives,

*'They want to get the outcome they've got the funding for, I think it can be biased research.'* (London)

*'I feel like any researcher is bound in most cases to be coloured by whoever is paying them.'* (Edinburgh)



*'Because they've got pressure, targets. If they're going out and saying right we're going to do this then, not necessarily tunnel vision but they're searching and searching and searching to meet that requirement.'* (Edinburgh)

### 5.2.3 Reasons for a lack trust in charities

For some participants, their lack of trust in charities to develop genetic technologies grew as they discussed how charities are funded or what the motivations of their founders or donors might be. This led some to shift from a 'charities just do good for the world' stance, to something more nuanced and less blithely accepting. For others, their scepticism was based on direct or second-hand experience of working with charities, or a sense that they can be guilty of not scrutinising what they fund sufficiently.



#### Influenced by donor or founder of charity

As with privately funded academics described above, some participants believed that charities could also be subject to the over-zealous demands of the charity founder or large donors which would influence what they fund,

*'With charities, there is a potential to really pervert things, you could say this is my charity looking into something, and this is the money, you'd better be finding things out, otherwise your funding is going to dry up.'* (Norwich)

#### Money no object so less effective

Compared to business or universities, that have to justify every penny they spend, some participants felt that some charities are so awash with donations that they could be less effective at targeting their research at projects with promise of success,

*'It doesn't matter that that experiment failed, there's another £2bn coming next week. They've got less to lose. Less at stake, in my opinion. They get tax relief from the government, so the more money they spend, the more they get back.'* (Norwich)

#### Have an agenda to protect

Some participants criticised charities for working in silos and their own way of doing things, rather than collaborating with others and feared this way of working would affect their approach to genetic technology,

*'In terms of actually judging their work through a level of scrutiny that people would have, its almost impossible to do that. There's many issues that you have, especially if you look at aid for example. And you have aggregate issues where charities are developing lots of different things at certain times and complicating issues where actually one simple vocal voice would be better. And I worry about them ring-fencing or protecting their livelihood as a charity by the very nature of the work they do.'* (Edinburgh)

## 5.3 Most trusted to inform and advise on uses for genetic technologies

Due to their knowledge, expertise and dedication to the profession, university academics scored highly in the context of information provision as well. In the dialogue other trusted parties to provide information and guidance on genetic technologies included regulatory organisations and professional/specialist networks. The survey results chime in some respects with the workshop discussions and show that that universities ranked first amongst all organisations (43%) in terms of trust to advise and inform. However, the other actors had similar levels of support, with businesses working on or funding research on genetic technologies (16%) ranking as the second most trusted, closely followed by government bodies/policymakers (14%), regulatory organisations (12%) and charities and campaigning organisations (9%).

Dialogue participants saw regulatory bodies as being impartial and rigorous and therefore well placed to provide balanced information and guidance. In London the ranking included advisory bodies, which took the lead as the most trusted actors for the provision of information and guidance for similar reasons to why participants in Edinburgh and Norwich ranked professional networks highly: they bring the views and expertise together of people who have worked in the field for many years and have expertise to communicate about their specialism.

### 5.3.1 Reasons for trust in university academics and researchers

Pure information, unfiltered because they work on the frontline

Information coming from university academics and researchers was seen to be coming from 'the source' and therefore to be purer than that coming from other organisations who might filter it to suit their own ends. The fact that it is these people who are performing the actual experiments gave further credence to the information they would impart,



*'The scientists, they're the ones who have experimented, they're the ones that know that that's got that side effect, and this'll make you sick and this will work and that won't work, even before it's regulated.'* (London)

*'I put both universities, academics and the privately funded academics and scientists because if I want to be told about a subject I want to hear it from the experts with first-hand knowledge, not the second hand from the people who haven't done the research.'* (Norwich)

Reputation linked to work

Participants believed that the research work of a scientist is intrinsically linked to their name, reputation and future career prospects. Therefore, it is in their interests to be open about what they have done and how it has been achieved,

*'You like to think that scientists want to understand the world, and they work without any financial gain, particularly, although I'm sure there will be, but it's something they do for science. You want it to be, you want your name in lights, maybe.'* (London)

In the business of education

The fact that universities are ‘in the business of education’ supported some participants’ belief that their scientists would be best placed to advise and inform on genetic technologies,

*‘They have the gravitas to be able to speak on the subject and the public would be more trusting on them based on their skills, qualifications and knowledge.’ (Norwich)*

However, some participants, particularly in Edinburgh, challenged the discussions on universities’ abilities to communicate with the public on genetic technologies, describing them as being elitist and lacking communication skills,

*‘I think that they like don’t have a platform to like, share their research adequately with the masses because it’s quite like, an elitist thing, and an elitist audience.’ (Edinburgh)*

*‘I feel like there’s a huge amount of people, like in the public, that can’t necessarily relate to what a university lecturer is saying.’ (Edinburgh)*

### 5.3.2 Reasons for trust in regulatory organisations

#### Impartial



In all locations, regulatory organisations’ impartiality was seen as a strength when it came to advising on and informing about genetic technologies. The impartiality is drawn from participants’ perceptions that regulators have a clear set of standards to apply to work on genetic technologies and therefore will not be swayed in their purpose,

*‘They’re quite impartial, because as a regulatory body, they’re not beholden to the organisations. That was another thought I had, if they’re regulating a laboratory or a business that is producing genetic technologies, then they’re quite prepared to take action against that organisation, so they’re going to be independent.’ (Norwich)*

*‘They still stick to their protocols or whatever and say no we’re still going to evaluate it from our own point of view to make sure that we’re happy, so I guess that kind of links in to the accountability that exists.’ (Edinburgh)*

#### An overview of everything that is happening

The role of regulatory organisations as an ‘all seeing eye’ on genetic technologies gave them a bank of knowledge, participants’ felt, that could be drawn on to provide information on the technologies,

*‘They should know what’s going on, what’s happening, they’re controlling it, and they should know what’s happening, why it’s happening.’ (London)*

*‘They would have a sort of overarching view of everything that was going on rather than a specialist knowledge of one thing and they’d be able to regulate what was acceptable and what wasn’t and rules and regulations and fining and restricting licences of people.’ (Norwich)*

However some participants in Edinburgh and Norwich wondered if regulatory organisations could be too risk averse to properly inform on the latest advances in genetic technology or, in fact, should focus on their regulations and leave advising to other actors,

*'I wonder if they could be a bit risk averse, because they're so open to accountability and scrutiny and they don't want a disaster to be blamed on them. Maybe they curtail innovation a bit.'* (Edinburgh)

*'If it's advising on the uses of genetic technology, I saw their role more as the control and standards in place.'* (Norwich)



### 5.3.3 Reasons for trust in professional/specialist networks

Wide range of experience to draw on

Professional/specialist networks, including organisations such as the Royal Society, were given widespread support for advising and informing on genetic technologies because of their perceived wide range of experience and opinions within the organisation. This range of views brought with it healthy debate and challenge that meant that genetic technologies would be both held to account and explained by the experts in the field and in related fields,

*'Because it's a collaborative of multiple professionals, and actually, it's more than one necessary opinion. I think the more members' input you've got, the less biased it could be.'* (Norwich)

*'In order to inform and advise like a really, really wide spectrum of people, I'd trust professional networks.'* (Edinburgh)

Independent

Some participants also saw professional/specialist networks as independent, because they don't have a financial interest in the technology,

*'I saw them as being quite independent, and they have a voice that isn't clouded by funding or any other agenda.'* (Norwich)

Communication expertise

Those participants who thought that university academics may be too elitist or specialist to inform the public on genetic technologies expected professional/specialist networks to be better at this role. This was because it was felt that one of the key roles of these networks was to disseminate the work of their members to the wider world,

*'It would be nice if the professionals could like, handle the communications but they were informed by the research, by the university researchers. It's just that there's like no point having a big awareness raising campaign if people aren't going to listen to it or think that it's like, engaging and interesting and well put out.'* (Edinburgh)

### 5.3.4 Other actors mentioned: charities, government and business

Fewer participants mentioned organisations such as charities and business as trusted to inform, but for those that did their rationale was as follows. Charities need to communicate their innovations to keep donations flowing in,

*‘For my point of view, they live on it, to inform us, like the British Heart Foundation; it's their lifeblood to inform us about it, so we donate more.’ (London)*

In Norwich, a handful of participants said they felt that government should be trusted to inform and advise on genetic technology because of their overview of the sector and because of a perception that that are more scrutinised today than previously,

*‘They're the ones who are setting the legislation and the safeguarding side of things, they've got to know about it and give information about it, and they should be trustworthy.’ (Norwich)*

*‘There's a change going on, I can sense it. Whereas before the government was very much untouchable, now they'd be openly challenged.’ (Norwich)*

In Edinburgh, a small number of participants spoke up for business's ability to inform on genetic technologies, although somewhat reluctantly in one case, because of their selling abilities and because they might know the technology best, having developed it,

*‘Best for communications would be business, I mean at the end of the day no one's better at selling. But that's not my answer, but still, if we're looking at it realistically who would develop a strong communication strategy that reaches people, it would be business.’ (Edinburgh)*

*‘You can look at a business that is developing technology, and maybe they know best how to use it, so from that point of view they might be better to advise on the actual practical use of it.’ (Edinburgh)*

In the survey, businesses working on or funding research on genetic technologies were seen as the second most trustworthy source of information and advice on genetic technologies by 16%, which demonstrates that the survey respondents were more trusting of businesses as sources of information and advice on genetic technologies than participants in the dialogue.

## 5.4 Least trusted to inform and advise on uses for genetic technologies

Across all locations businesses were least trusted to inform and provide guidance on genetic technologies and their uses. There was a sense that businesses are likely to hold back information that potentially undermines their ability to increase profits. Some participants stressed that businesses communicate via their marketing/PR teams rather than scientists, which potentially reduces the objectivity of messages.

In Norwich and Edinburgh there was strong scepticism that government bodies/policy makers would provide unbiased information as their communications framework is shaped by political motives. Charities and campaigning organisations scored less well as providers of information and guidance as participants acknowledged they often have an agenda and are therefore less likely to be impartial. This chimed with the survey findings which showed that charities and campaigning organisations were the least trusted by respondents to provide information and advice about genetic technologies. In the survey, Businesses working or funding research on genetic technologies were more trusted than charities with 16% of respondents ranking them first compared to 9% for Charities and campaigning organisations.

#### *5.4.1 Reasons for a lack trust in business*

Money motive = half truths

When participants discussed their lack of trust in business their main concerns stemmed from the profit motive, which would drive which technologies to invest in and the kind of information they would share, which would put their technologies in the best light,



*'They want to make money. So, anything else could be half-truths, but the main thing is they want to make money.'* (Norwich)

Participant A: *'We kind of understand that businesses are working on genetic technologies because businesses exist to make a profit, so it's in their interests to only...'*

Participant B: *'...Not to be totally transparent.'*

Participant A: *'...and to only give certain sides of the argument.'* (Edinburgh)

Focused on the benefits of their technology – one sided

There was some concern amongst participants that if business sought to inform the Government about genetic technologies, they would do it in a lobbying fashion to clear the path for their own technology to be approved or promoted,

*'I think to advise you'd have to have a look at the larger picture, the broader aspect of it, whereas that's not a business's purpose, its purpose is to find the key areas it can profit from, so yes, you would advise on specific areas that would benefit yourself.'* (Norwich)

*'They're not going to give a balanced view, it's going to be promoting their product rather than saying oh this is where we are now, we're not quite sure about it because they're wanting people to buy it and for it to be successful.'* (Norwich)

PR people do the communicating

In contrast to the endorsement of scientists as the source of unfiltered information, many participants saw information from business as being 'spun' by marketing people,

*'With the business as well, it's more likely to be a non-scientific person speaking, so coming from marketing and communications.'* (Norwich)

While most participants did not discuss in depth any differences in how they perceived big business vs smaller businesses or start-ups, most negativity seemed to be directed at big business,

*'Lots of problems that exist already with like, just like big companies having lots of control other things and trying to work out in this new field, before it's been properly set up, to get it going, to try and work out how there could be like safeguards in place to prevent like what happens already in every other sector.'* (Edinburgh)

*'I have an iPhone but I don't trust Apple to protect, I don't trust my mobile phone provider, but I use the technology because I don't really have an option it's the society we live in, so you know, I use businesses everyday but it's more through necessity rather than through desire or choice.'* (Edinburgh)

However, one exchange in Edinburgh indicated that business per se is distrusted, even if started by a scientist,

Participant A: *'Would it depend who the owner was? What if it was a prominent university academic who decided to open a business because that was the only way he could turn his own technology into a viable product, because that does occur.'*

Participant B: *'No, I would still trust them least, because it doesn't matter if it's James Dyson developing stuff which is amazing like hand-dryers which are terrific, or Richard Branson who's developing Virgin Trains which is just dreadful, I would still seek to gain an understanding of the business from outside sources who I would trust them objectively least. But that's not to totally damn them by saying they're all evil.'* (Edinburgh)

#### **5.4.2 Reasons for a lack trust in government bodies/policy makers**

Subject to lobbying by companies and donors

For some participants, the government of the day would always be influenced by the donors to the ruling political party, which could conceivably be genetic technology companies,



*'They're influenced, they've got donors you know, I mean there are third parties actively investing money into parties, that conflicts everything. Whether that's conscious or not, AquaBounty comes along and gives the Conservative party or the Labour party two million pounds, it's not really a small amount of money is it, it's going to have some weight.'* (Edinburgh)

Slow to act in the social interest in the past e.g. tobacco

In both Edinburgh and London, participants held up the tobacco industry as an example where government was seen to have been too timid in its protection of public health, attributed to strong lobbying and the tax contribution made by tobacco purchases. These participants, were concerned

that equally strong lobbying from genetic technology companies could lead the government to making decisions that weren't in society's best interests,

*'With the lobby for tobacco, for years they tried to bring research to say it was dangerous against, you know. It had health consequences that were dangerous to the population and for generations that legislation and things to research it was lobbied against by the American tobacco companies.'* (London)

Participant A: *'They've known smoking was bad for your health for quite a long time.'*

Participant B: *'But they got the taxes...'*

Participant A: *...'It was 2006 when the ban came in, but it took so long between actually knowing it was bad for your health and that actually happening.'* (Edinburgh)

Protecting their reputations and constituencies

The perceived self-interest of politicians also came up in discussions as a reason not to trust politicians to inform or advise on genetic technologies. Some participants thought that MPs would either favour or protest against a technology based on the interests of their constituents, rather than the wider country or would be too risk-averse to support an emerging technology that the public might be nervous about,

*'They're not going to coming out and support something that could potentially be controversial amongst voters.'* (Norwich)

*'I'm more likely to believe the scientists and the academics with the information than the government, because they'd put a particular spin on it, and then if they get it wrong, they'll deny it and U-turn.'* (Norwich)

Tick box exercise of informing

In Edinburgh, participants talked about their sense that governments' style of communicating was too passive and web-based and therefore not suitable for an important topic such as genetic technology,

*'Government bodies or like, regulatory organisations and stuff like that, that sort of put something on their website to tick the box of informing people but that doesn't mean that it's got the message across.'* (Edinburgh)



## 5.5 Trusted to regulate genetic technologies

As part of the exercise in which participants put themselves in the shoes of a range of stakeholders, discussions were held about who people would trust to regulate genetic technologies.

Multidisciplinary panel including members of the public

There was a strong view amongst dialogue participants that genetic technologies should be regulated by a multidisciplinary panel with representatives from all stakeholders to ensure a balanced view: scientists, ethicists, professional networks, government, charities and businesses. As someone in Norwich said,

*'Yeah we just felt, looking at each one, anyone could have an agenda of their own that they might want to push that wasn't necessarily in everyone's best interests that's the first thing that we kind of went to that we were talking about, it was just kind of like I want everyone on it if I'm honest.'* (Norwich)

And in Edinburgh,

*'I think it's a good idea [a multidisciplinary panel] because it's true, like every organisation does like have their own self-interests so if you put it all together then obviously it's like a collective agreement as opposed to like the one vested interest.'* (Edinburgh)

In the animal applications dialogue in Edinburgh and the plant applications sessions in Norwich, participants felt it is important that a multidisciplinary body for the regulation of genetic technologies includes specialists, i.e. vets for the regulation of animal applications and farmers for plant/crop regulation,

*'Why vets? Well they have a compassion for the welfare of the animals and the academic background and research.'* (Edinburgh)

*'Farmers and everyday gardeners, they know their stuff.'* (Norwich)

All the groups in London felt strongly that patients should be included in regulatory panels, particularly patients or representative from families who might carry a genetic disorder,

*'It should also include people that have, or are at risk of developing diseases. They're going to be the ones who would benefit most, it's best to get their views, just for more balance.'* (London)

*'If it's something specific, as well, if you're looking at one specific disease or something, then somebody with experience of that, not just a public member.'* (London)

Involvement of members of the public in a regulatory body was important to participants in the animal and plant applications workshops as well. There was no doubt that advances in genetic technologies are going to affect people's lives one way or another, whether through human, plan

or animal applications which therefore requires their involvement in a multidisciplinary regulatory panel. As someone in Edinburgh said,

*'I think public consultation is really important because people can make assumptions about what our wants, desires, fears or hopes are but it's better coming from the horse's mouth. And at the end of the day, it's the public that's going to have to accept what happens, it's going to affect their lives directly so regardless, you know, they should really be part of that process, shouldn't they? It's a democracy.'* (Edinburgh)

There were split views over whether businesses should be involved. Concerns ranged from corporations having too much of a vested interest to be objective about their own products, as reflected in the following words of a participant in Edinburgh,

*'My thinking is, let's say we were evaluating AquaBounty and we are evaluating if they fit our criteria for regulation, having one of their members on the board that decides if they do or don't is inherently biased and they have a clear conflict of interest.'* (Edinburgh)

For those who felt that businesses do need to be part of a multidisciplinary panel that regulates genetic technologies the main argument was that their membership would ensure greater accountability. A participant in Edinburgh had discussed this with a group of friends and reported back,

*'They talked [...] about fears over who would regulate it and who should regulate it and whether private concerns or governments would be better. Some had views that private companies would be better because they had an incentive to make money and therefore would be more careful over making sure what they did was right.'* (Edinburgh)

A multidisciplinary panel that regulates genetic technologies has to have gravitas. As one of the groups in Edinburgh discussed,

*'We said a committee chaired by a cabinet member, so they've got teeth, metaphorical teeth.'* (Norwich)

### Transparency

There was an expectation amongst dialogue participants that a regulatory body for genetic technologies would be fully transparent about their decision-making,

*'I'd expect to see, whoever you have full disclosure of the minutes from each...it should all be on public record. Where the funding has gone, what the funding has done, like an annual review of each project to make sure that the money was still going into the best place possible. I have no idea who you'd put on it.'* (Norwich)

### Global body

The vast majority of participants in the dialogue felt strongly that a regulatory body for genetic technologies should be global,

*'We need an overall worldwide body to oversee this, and all countries need this. Because otherwise you're going to have rules here, rules there, rules in America and rules in China, all different. Scientists will say, I want to research this, but I can't do it here, I'll go there. So unless you have an overall authority, because it's worldwide, you can't just say, it's not in isolation.'* (London)

As we have seen in section 3.5 this chimed with the findings of the national survey in which 81% of respondents agreed that there should be a global regulatory framework

# 6. Impact of the dialogue process

## Chapter 6 summary

In chapter 6 we report on observations made by the HVM team in participants increasing interest in genetic technologies the more they learned about both their history, the different techniques and the (potential) applications.

The evidence received by participants, contribution of the expert witnesses, discussion with their peers and the dialogue process itself all allowed for people to shift in their perspectives, becoming more open to discussing aspects of genetic technologies which may previously have been completely unknown to them.

HVM observed participants moving along a learning curve from:

- Not knowing anything at all to feeling they would be more aware of/interested in the subject in the future
- Fear to cautious optimism
- Thinking that this was another tick box consultation exercise to considering that their voices have been heard and will be of value in shaping the future direction of the work of the Royal Society in engaging the public in science.

When comparing the hopes and fears expressed in round 1, with the views about acceptability and unacceptability when developing genetic technologies in round 2, five shifts in participants' thinking were noted. These are explored in the chapter under the following headings:

1. An increasing sense that regulation that is too oppressive can inhibit progress
2. A need to understand the cost impact of genetic technologies for the UK and global economy
3. Genetic technology is here and developing fast, how do we balance it with other interventions?
4. The risk of large corporations overly dominating the health and food sectors
5. Thinking about what future generations will say about the decisions made now on genetic technologies.

The chapter ends with a number of surprises that participants reflected on in their exploration of genetic technologies. Their first surprise was how little they knew about genetics and associated technologies. A second surprise, linked to the first, was the wide range of opportunities on every aspect of modern life around the world that could be affected by developments in genetic technologies. Thirdly participants were taken aback by how far science has progressed since the 1950s with the discovery of the structure of DNA. In all locations, but most vocally in Norwich, people were initially astonished to find that there is no global regulatory system for the monitoring and approval of genetic technologies. The final surprise referred to in the chapter is that the Royal Society took such serious steps to genuinely engage the public on these issues.



## 6.1 The dialogue process

As noted in Chapter 2 of this report, the national survey shows that there is a substantial interest in society in genetic technologies, with 46% of the population being fairly interested and 24% very interested. The independent evaluation commissioned by the Royal Society to run alongside the public dialogue will assess the impact of the dialogue process on participants in detail. This section is therefore intended to provide a set of observations made by the HVM facilitation team as they delivered the dialogue in the three locations and having analysed the data that have emerged from it.

In the public dialogue the HVM team observed an increased interest in genetic technology and its applications the more participants learned about both the history of the technology, the different techniques and the (potential) applications. For most dialogue participants it was the first time they had an opportunity to learn about any aspect of genetic technologies, find out about the science and discuss the potential uses of the technology as a contribution to solving global challenges. As one participant said,

*'I think I am a little bit more informed and perhaps a little bit more open to the concept whereas before I was definitely coming from a more fear perspective. I just saw it as mutation rather than a development.'* (Edinburgh)

The evidence received by participants, contribution of the expert witnesses, discussion with their peers and the dialogue process itself all allowed for people to shift in their perspectives, being more open to discussing aspects of genetic technologies which may previously have been completely unknown to them. HVM observed participants moving along a learning curve (see figure 51), from:

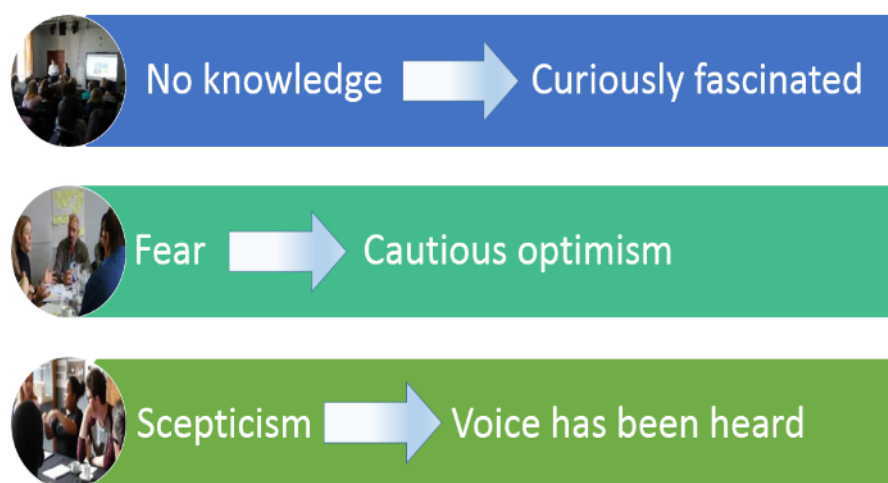


Figure 51: The public dialogue learning curve

- Not knowing anything at all to feeling they had learnt enough to do their own research on the subject and keep track of future developments
- Fear to cautious optimism
- Thinking that this was another tick box consultation exercise to considering that their voices have been heard and will be of value in shaping the future direction of the work of the Royal Society in engaging the public in science.

Participants made comments such as,

*'I never had to think about genetic technology. To sit with people who have thought about it has been challenging, rewarding and ultimately very stimulating and educational.'* (London)

They felt that sharing their fears about genetic technologies and discussing their negative thoughts was very productive,

*'I didn't know that much at all about genetic technologies initially. I learnt so much. We shared our fears and there was a lot of negativity initially. But it was great to see how the group dynamic worked, and it was a great learning curve. We then spent four weeks away and I'm actually learning more and researching more and I'm speaking about it more [with friends] which I wouldn't have done before.'* (Norwich)

and that it was the experience as a whole which was enriching. As a London participant put it,

*'It was really informative and has given me an opportunity to listen to people who are really experts in the field, listen to their insights as well as their knowledge as well as talking to peers about our fears, concerns and hopes for a future with genetic technologies. The process has been, for me, very positive.'* (London)

We saw as the two rounds of workshops progressed participants were positive about their experience. Some felt that other organisations should take the Royal Society's lead and do more to engage the public on scientific and technically complex issues. As one participant said,

*'I think the process is very important. I think for the scientists and wider legislative bodies one of the most important things you can do is engage with society and find out what they really want. I think there is a lot of scope and more institutions should be doing similar things.'* (Edinburgh)

You can see his comments in the video clip to the right.



In summary it was evident to the HVM team that participants welcomed the opportunity to take part in the dialogue process. There was a very positive feeling towards the Royal Society for having considered it important to speak to the public about an issue as technically and socially complex as genetic technologies. As one participant said,

*'This is a positive thing that the Royal Society are carrying out to evoke a response from the general public.'* (London)

And another commented,

*'I think it is great that you are engaging with lay people and I am able to have a say, influencing what happens in the long term.'* (Edinburgh)

The three main aspects that HVM identified as being particularly positive are summarised in figure 52, beginning with respect for a process that was genuinely engaging for them.

People recognised the value in having time for reflection in between the two rounds of the dialogue.

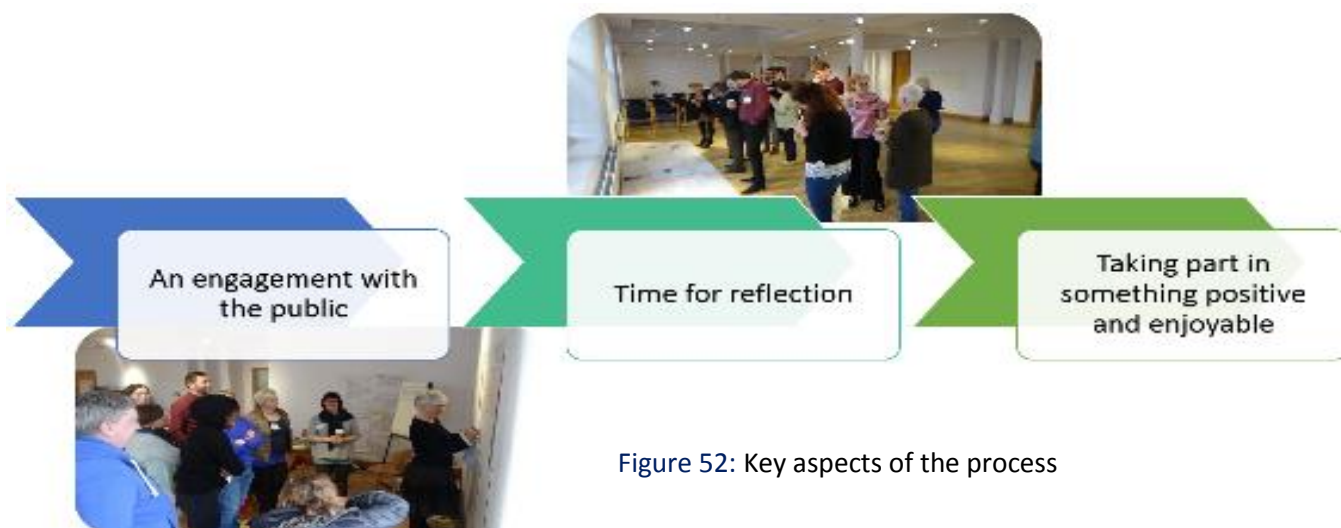


Figure 52: Key aspects of the process

*'In the first session we had to deal with huge issues but having that space to talk with my friends, to think about it and to do my own research was incredibly valuable because now, today, I've got a lot more out of it. I have learnt from it.'* (Norwich)

They also mentioned that for them the process and the subject matter had been not only engaging, but enjoyable as highlighted in these clips from Norwich and London participants,



## 6.2 Changes in attitude

When comparing the hopes and fears expressed in round 1, with the views about acceptability and unacceptability when developing genetic technology in round 2, shifts and developments in participants' thinking were noted. These are broadly summarised in figure 51 and described in the five points below:

### 1. An increasing sense that regulation that is too oppressive can inhibit progress

In the round 1 discussion on fears, some participants were extremely concerned about the lack of global regulation for genetic technologies. This concern changed somewhat when expert witnesses provided more information on the current regulatory system. In the use of plants for food for example, participants were unaware that using traditional methods to breed a new variety of plant are not regulated within the current system. Some of the case studies that participants examined during the workshops included information on how long it took/is taking for various genetic technologies to be approved for use, such as the Atlantic salmon and the 'Golden Rice' examples presented as case studies in Edinburgh and Norwich respectively. Whilst participants wanted products and treatments to be safe and sustainable, some felt that potential solutions to global challenges and pressing human conditions should not be held back by red tape, particularly if that red tape doesn't have the UK's interests at heart.

### 2. A need to understand the cost impact of genetic technologies for the UK and global economy

As participants had more time to discuss the consequences of using genetic technology, there was a stronger desire to see evidence of how the financial impacts of these technologies are being factored in. Genetic screening of humans, in particular, triggered discussions about this. Whilst the cost to screen someone for a genetic condition might be a certain amount, could the costs to treat the condition be an even higher figure? If so how are policies and medical practices being adapted to take these costs into account?

### 3. Genetic technology is here and developing fast, how do we balance it with other interventions?

With participants being exposed to a range of examples of the use of genetic technologies in the case studies, the contextual presentations and the information gained from media coverage between the rounds, the impression was widespread that genetic technologies were developing rapidly. This led to a hope that society would not throw all our talent and resources into genetic technologies, but continue to consider them as part of a range of options for tackling global challenges such as inequality, climate change, tackling health issues such as obesity and keeping populations safe.

### 4. The risk of large corporations overly dominating the health, food and energy sectors

Learning more about work being done in genetic technologies, led to growing fears amongst some participants that the food and health sectors could be more dominated by large, international pharmaceutical/technology companies. They perceived that this would pose a risk to smaller, more local companies and suppliers who would be forced to buy the technology because their products/processes could no longer compete, or that they would be forced out of business altogether.



## 5. Thinking about what future generations will say about the decisions made now on genetic technologies

Thinking about future generations and what they would think about the decisions made about genetic technologies now made some participants stop and think more deeply about what they saw as acceptable and unacceptable. Some felt that people in the future would look back and be shocked at our cautiousness and how we could have intervened earlier and used genetic technology to tackle issues such as malnutrition with Golden Rice or taken away the fear of dying of a heart attack by editing out cardiomyopathy. Equally some participants thought society was at risk of denying future generations' choice by giving too free a hand to genetic technologies that could yield unintended consequences to the environment, biodiversity and what it means to be human.

## 6.3 Surprising elements of the dialogue

Given that participants came to the dialogue with very little knowledge of genetic technologies they were undoubtedly surprised as they learnt more through the contextual presentations, discussions of the case studies and interaction with the expert witnesses.

### Recognition of the public's limited knowledge

Of first and increasing importance to participants as the dialogue developed was discovering just how little they did know about the subject and the extent to which what they did know had been informed by what they perceived to be largely unreliable information in the media and in discussions within their networks. This was very apparent in the warm-up discussions at the beginning of round 2 when participants were asked to report on the conversations they had had with friends and family.

*'How do I know that that's just media talking nonsense?' (London)*

As one participant stressed,

*'For me the biggest thing that [the Royal Society] need to bring out of this is that people need to understand about genetic technologies more. There is so much misinformation out there. People need to understand what genetic technologies can do, the safety of the genetic technologies we have, and the impact that they could have on our world and our planet.'* (London)

As a result participants felt there should be far more education, from an early age, on the basics of genetics so that people are more equipped in later life to understand the evidence and make a judgement on which information is to be trusted.

### Range of potential uses for genetic technologies

A second surprise was the wide range of opportunities on every aspect of modern life around the world that could be affected by developments in genetic technologies. In Edinburgh, given the importance of salmon to the Scottish economy, participants were particularly surprised that they had not heard that permission had been given for AquaBounty to genetically modify salmon and that it was now being sold in Canada.

*'I guess kind of in regards to the information, I think a lot of the people I was chatting to were kind of talking about the fish, and the fact they'd already been genetically modified, like no one had told*

*them about it. And it's not something they were aware of, they were kind of surprised to know that it was something that was already going on.'* (Edinburgh)

Another participant in Edinburgh summed up well their surprise at the range of topics covered in the dialogue echoing the range of potential uses there for genetic technologies as the science develops,

*'I've learnt loads and been surprised in some of the directions conversations have taken. We started with the uses of genetic technologies in animals, and we've zoomed out in lots of fascinating directions, from genetic technologies, to food security, climate change, corporate profit, and lots of other things.'* (Edinburgh)

#### Extent of scientific progress

Thirdly participants were surprised how far science has progressed since the 1950s with the discovery of the structure of DNA. The timeline setting out developments from 40,000 years ago to the present day increased their surprise on this issue.

In all locations, but most vocally in Norwich, people were initially astonished to find that there is no global regulatory system for the monitoring and approval of genetic technologies. For example two participants in separate groups in Norwich said,

*'Before things develop further you need to have a framework of what it's used for, who's going to monitor it and if something goes wrong what steps are in place to deal with it and inform the public? I was shocked when (the expert witness) said there's no world body that regulates it.'* (Norwich)

*'My mates were all concerned and surprised that there is no overall regulatory body. That was something I was surprised about.'* (Norwich)

This is symptomatic of how seriously participants took recent developments in this area. Their surprise continued when they learnt how little regulation there is generally on, for example the cross-breeding of plants for food. This highlights a point about terminology. When participants spoke about regulation they were at times referring to legislation and hard law, but at other times they wanted to see guidelines or ethical frameworks under which further research or and trials are undertaken. As we have seen in the previous section, they did not wish to restrict the work of scientists unnecessarily. Of primary importance was ensuring that all risks and consequences are considered and that the public is kept informed of both positive and negative developments.

#### Royal Society's commitment to genuine public engagement

The final surprise to be mentioned here is that the Royal Society took such serious steps to genuinely engage the public on these issues. They were surprised about the extent to which they had been listened to. A sample of 18 interviews to camera were conducted in each location. In these interviews participants were asked what their hopes were for the report being produced to reflect their views on genetic technologies. Above all participants said they wanted to know that now that they had been engaged with, their views would influence policy and future engagement on genetic technologies. One participant summed up the views of many by saying,

*'I hope the Royal Society take away the views of those who have participated and are able to use those views to influence the decision makers.'* (London)

His full comment is available here:



# 7. Conclusion

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Recent scientific developments have made making, adapting and understanding genetic material much easier, faster and cheaper. As Emma Woods, Head of Policy at the Royal Society said in an introductory film,

*'Science can tell us what can be done with genetic technologies but everyone, scientists, society, you should be part of a conversation about what should be done with genetic technologies.'*

This study has identified the conditions that moderate public support for some possible uses of genetic technologies.

## 7.1 Cautious optimism in society for genetic technologies

HVM concludes from the qualitative and quantitative elements of the research that there is a cautious optimism in society for genetic technologies and their uses. This was illustrated in the posters created by participants in each of the locations, who had discussed in detail the pros and cons of a specific use of genetic technologies (see chapter 4). Quotes selected from newspapers and magazines included: *'Change the world'* (London), *'Brighter futures'* (London), *'Are you all ready for take-off?'* (Norwich), *'A dawning of a new era'* (Edinburgh).

Support is particularly high for the use of genetic technologies to improve human health, reduce global inequalities and reduce or help reverse the impact of climate change. Each of the nine small groups (3 per location) included in their visual output a desire to use genetic technologies to help tackle global challenges, e.g. *'On a mission to save humanity'* (Edinburgh, used in all animal case studies); *'We can't bury our heads in the sand'* (Norwich, case study Reducing vitamin A deficiency); and *'To eradicate all disease'* (London, case study Testing for genetic disorders).

This sense of cautious optimism was validated in the national survey in which 24% of the respondents indicated they are very interested in genetic technologies and 46% fairly interested (see figure 7). 32% of respondents were very interested and 48% fairly interested in scientific developments to address global challenges including climate change, disease and famine.

## 7.2 Caveats for support of genetic technologies

Discussions in all locations showed that caveats for public support of genetic technologies were similar whether related to considerations about human, animal or plant applications. They are discussed in chapters 3 and 4 of the report and summarised below:

- The need to focus on essential solutions that enhance society
- Genetic technologies should be considered as part of a package of solutions for global challenges
- There should be equity of access to the technologies
- The principle of 'no harm to the environment/ecosystem' must be applied
- Importance of managing expectations

- Animal welfare standards must be maintained
- Information must be accessible and available to the general public
- Effective regulation, legislation and ethical guidance must be put in place.

### 7.3. Opportunity to inform the public about genetic technologies

The survey tells us that 28% of the population had seen/read/heard (on the news, in a paper or on social media for example) any information about genetics or genetic technologies in the last month.<sup>8</sup> This is in line with findings in the dialogue (see section 6), where many participants didn't know much about the subject at the start of the process. This shows there is a huge opportunity to inform the public about genetic technologies and their uses. Dialogue participants made it clear that fear of the unknown impacts heavily on people's views. Along with respondents in the survey, they indicated they have significant trust in university academics, scientists and researchers for the development of genetic technologies as well as for the provision of information and guidance. However, scientists and professional networks need to bring the public and media with them to ensure clear and accessible information is provided to present a balanced well-rounded view in society about genetic technologies,

*'The media has turned it into a monster. We've all been saying Frankenstein, because that is the word that we've heard, and seen infiltrated into our minds. I think the media has played a large role in our fear. That's why we can't hear the voice of the academics, or the voices of the ethicists, because the media suddenly turned it into a by-line.'* (Norwich)

The following conversation in Norwich illustrates these considerations further,

Participant A: *'It's the boogie monster....'*

Participant B: *'Well yeah, what you see in your mind's eye is still a picture of a mouse with an ear on it. That's like the media version of GM isn't it?'*

Participant C: *'You're right, that's the default image for that. Or Dolly the sheep was the other.'* (Norwich)

The group came to the conclusion that there needs to be a mechanism for two-way communication between the scientific community and members of the public so that public perceptions are known and taken into account when decisions are being made about the use of genetic technologies,

Participant D: *'It's two ways. We should be informing them what we know, and what we believe, and equally, they should be informing us what they're finding. A two way system, where currently it seems to be a one way system.'* (Norwich)

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<sup>8</sup> The survey showed that people aged 18-34 (39%) are more likely to have heard news about genetic technologies than the 35-54 (25%) and 55+ (20%) segments

They talked about ongoing dialogue between the scientific community and members of the public alongside effective education and briefing of the media, led by a professional organisation like the Royal Society,

Participant B: *'Yes, and I would say with education, it should start with bodies like the professional specialist networks, like the Royal Society, where we can improve the education right from schools and upwards, so we don't end up with this miscommunicated lack of trust in the topic from the start.'*  
(Norwich)

## 7.4 Updating the genetic technologies narrative

The public dialogue demonstrated that genetic technologies applied to treating or preventing human disease, reducing global inequalities and combatting climate change are leading to a shift in attitudes towards genetic technologies, which were previously best known for their application to plants and animals for food.

Although there are still remnants of fear around the consumption of genetically modified food, particularly concerning its safety for human consumption and in the food chain, we also found that there is widespread support for the use of genetic technologies as part of a package of solutions to achieve a more equitable food future for a growing world population.

The growing awareness and support for applications in humans to prevent and cure disease, reduce inequalities and in steps to combat climate change means that there is a real opportunity to update the genetic technologies narrative and have a more informed conversation with the public about genetic technologies and all of their potential applications as part of a package of solutions to unprecedented global challenges. This will be valuable to ensure that this technology can be used to deliver public goods in a manner which has public confidence and builds on the desire shown by participants in the dialogue for science to advance and keep society moving forward.

## 7.5 The future for engagement on genetic technologies

To conclude HVM believes that the Royal Society has created a safe space in which to explore the complex landscape of genetic technologies, from ethical considerations to practical applications, and from trusted actors in the field to an effective regulatory framework. Building on these conclusions we recommend that this safe space continues. This could take a number of forms including:

1. Publishing a Royal Society response to this report demonstrating that the voices of those involved, particularly dialogue participants, have been heard
2. Encouraging those campaigning in the field of genetic technologies to work with them to engage the public in a balanced discussion of the issues involved
3. Using the resources developed as part of this public dialogue to devise mechanisms, based on dialogue methodologies, for various communities to take up their own discussions and create their own safe spaces to explore the potential risks, benefits and rewards of genetic technologies

4. Continue to engage the public meaningfully by talking publicly about the issues that people care about such as health, the environment and climate change mitigation and addressing global inequalities.

## 8. Acknowledgements

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