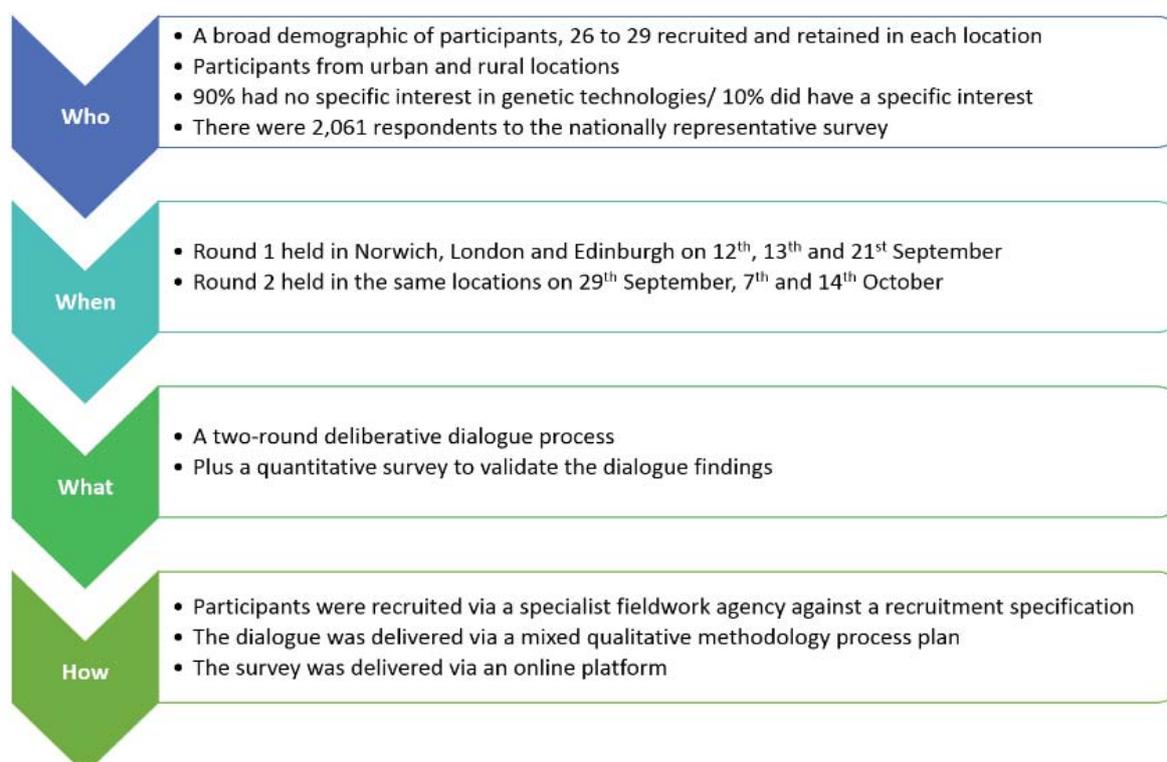# Executive summary

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:

Who
- A broad demographic of participants, 26 to 29 recruited and retained in each location
- Participants from urban and rural locations
- 90% had no specific interest in genetic technologies/ 10% did have a specific interest
- There were 2,061 respondents to the nationally representative survey

When
- Round 1 held in Norwich, London and Edinburgh on 12th, 13th and 21st September
- Round 2 held in the same locations on 29th September, 7th and 14th October

What
- A two-round deliberative dialogue process
- Plus a quantitative survey to validate the dialogue findings

How
- Participants were recruited via a specialist fieldwork agency against a recruitment specification
- The dialogue was delivered via a mixed qualitative methodology process plan
- The survey was delivered via an online platform

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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