



Department for
Business, Energy
& Industrial Strategy



Genome Editing for Human Health

Roundtable to explore future public engagement priorities

Briefing paper

Thursday 22nd March, 10.00 – 1.00

RIBA, Lasdun Room

[66 Portland Pl, Marylebone, London W1B 1NT](#)

Thank you for agreeing to attend the roundtable on the 22nd March.

The event is supported by the BEIS Sciencewise programme. The [Sciencewise programme](#) helps policy makers to deepen their understanding of the public's views on new and emerging areas of science and technology, through deliberative dialogue, enabling them to develop policies which take account of public opinion. The event is being run in partnership with the National Coordinating Centre for Public Engagement (NCCCPE). The [NCCPE](#) is funded by RCUK, Wellcome and the HE Funding Councils to increase the quality, coordination and impact of public engagement in the higher education sector.

We are delighted that we will be joined by such an expert and experienced group of people who are working in research, policy and practice, in a variety of roles, to realise the potential of Genome Editing for human health. We hope that by working together in a really focused way we can stimulate purposeful shared learning, and more importantly, identify an agenda for future activity.

This paper provides a brief overview of our plans for the roundtable. We hope you will have time to read through it in advance. We would welcome any comments in advance of the workshop. It contains a number of prompt questions for delegates:

- Does the representation of the field of Genome Editing research and application for human health (page 6) provide a 'good enough' map to help us describe the complex research landscape? Where does the activity you are involved in fit on that map?
- Does our summary of the key lessons learned from the public engagement to date reflect your understanding? What is missing or significant which we need to take account of? What do you think are the strengths and weaknesses of the work done to date?
- Looking ahead 3 – 5 years, what do you anticipate being the most significant developments in research, application and policy in the field of Genome Editing for human health? What are the implications of these for future public engagement?
- Are there specific actions which you think BEIS through the Sciencewise programme and/or other agencies should be taking to future proof public engagement in this area?

Simon Burall - Programme Director, Sciencewise

Paul Manners - Director, National Coordinating Centre for Public Engagement

Attending

We are delighted that the following individuals and organisations will be represented at the event.

Policy and practice

- Katrina Nevin-Ridley - Director of Communications, Genomics England
- Mark Bale – Genomics Science and Emerging Technologies, SRE, Department of Health and Social Care
- Patrick Middleton - Associate Director of Communications and Engagement, BBSRC
- Kathryn Brown – Assistant Director, BEIS
- Brigid Feeny - Assistant Director, Place Team, Science, Research and Innovation, BEIS
- Amanda Hunn - Joint Head of Policy, Health Research Authority
- Jonny Hazel - Policy Advisor (Wellbeing), Royal Society
- Mark Robertson – Director, Science Policy Compass
- Sandy Starr – Communications Officer, Progress Educational Trust
- Sarah Norcross – Director, Progress Educational Trust
- Rachel Brown – Policy Officer, Academy of Medical Sciences
- Anna Wilkinson – Research Officer, Nuffield Council for Bioethics
- Sarah Rappaport – Policy Adviser, Wellcome
- Heather Browett - Policy Officer, Wellcome

Facilitators and hosts

- Paul Manners – Director, National Coordinating Centre for Public Engagement
- Simon Burall – Programme Director, Sciencewise
- Roland Jackson – Senior Consultant, Sciencewise
- Suzannah Lansdell – Dialogue and Engagement Specialist, Sciencewise
- Diane Beddoes – Senior Dialogue and Engagement Specialist, Sciencewise
- Hally Ingram – Programme Manager, Sciencewise
- Tony Whitney - Public Engagement in Science and STEM Inspiration, BEIS
- Alec Weir - Public Engagement in Science and STEM Inspiration, BEIS

Researchers

- Andrew Webster - Professor in the Sociology of Science and Technology, University of York
- Kathy Niakan - Human Embryo and Stem Cell Laboratory, The Francis Crick Institute
- Pleasantine Mill - Group leader, Institute for Genetics and Molecular Medicine, University of Edinburgh
- Helen Sang - Chair of Vertebrate Molecular Development, The Roslin Institute and R(D)SVS
- Waseem Qasim - NIHR Professor in Cell & Gene Therapy, Institute of Child Health & Great Ormond Street Hospital
- Joyce Tait, Director, Innogen Institute
- Doug Higgs – Director, Weatherall Institute of Molecular Medicine
- Bruce Whitelaw, Genus Personal Chair of Animal Biotechnology, Roslin Institute
- Brian Bigger - Group leader Stem Cell & Neurotherapies Laboratory, University of Manchester
- Brigitte Nerlich, Emeritus Professor of Science, Language and Society, Nottingham University
- Amarpreet Kaur - Cambridge University
- Sarah Chan - Usher Institute of Population Health Sciences and Informatics, University of Edinburgh
- Julian Rayner - Director Wellcome Genome Campus Connecting Science, Group Leader Wellcome Sanger Institute
- Anna Middleton - Lead, Society and Ethics Team, Wellcome Genome Campus
- Gene Rowe – Independent Research Consultant, GRE
- Robert Smith – Research Associate (Social Dimensions of Synthetic Biology), Department of Global Health & Social Medicine, King's College London
- Gabby Samuel – Research Associate, Department of Global Health & Social Medicine, King's College London
- Lydia Teboul – Head of Molecular and Cellular Biology, MRC Harwell Institute

The focus of the roundtable

We plan to work through the following steps in the roundtable

1. Agree a shared representation of the 'field' of genome editing for human health (research and application)



2. Horizon scan key research and policy developments



3. Take stock of the public engagement that has been undertaken to date and the key lessons learned



4. Identify a strategic response to the above, agreeing how future public engagement activity might be better targeted and prioritised to address the opportunities and risks identified

We will present a simple mapping of the field (see page 6), which we plan to review and improve at the workshop.

Our goal is to ensure that we are all 'on the same page' in describing what we understand by Genome Editing for Human Health and how it is currently being researched, and that research applied.

Having reviewed the mapping, we will then start looking ahead.

We want your help to explore how you anticipate the field developing in the next five years.

From your perspective, what do you anticipate being the most significant developments in research and application?

What are the critical policy decisions that you anticipate having to be made in the same time period?

There has been a variety of public engagement and public dialogue projects undertaken in this area.

These include:

- Efforts to help the public understand this complex new area
- Efforts to consult with the public about the social and ethical implications of the science
- Efforts to involve the public in the development of policy and governance of the area

We have developed a synthesis of the key insights gleaned from these activities (pages 7 - 19), which will present and review with your help.

We want to identify and test what we think we already know, and to identify areas where our current knowledge is limited.

The last part of the roundtable will focus on what needs to be done to ensure that we are investing in appropriate forms of public engagement in this area, and coordinating this activity effectively.

Mapping the genome editing for human health research landscape

Is it possible to provide a succinct map of the key areas of activity currently underway in genome editing research and application?

1. Agree a shared representation of the 'field' of genome editing research and application
2. Horizon scan key research and policy developments

Domain	Focal points for investment and activity
Genome editing technologies	<ul style="list-style-type: none"> Engineered nucleases <ul style="list-style-type: none"> CRISPR/Cas9 (and derivatives) ZFNs TALENs Recombinant adeno-associated virus (rAAV) Homing endonucleases/ mega nucleases Programmable base editing
Human genome editing technology applications	<p>Basic research Genome-editing research conducted on human cells, tissues, embryos, and gametes in the laboratory.</p> <p>Clinical research Therapy by editing in somatic cells Therapy by editing in germline cells</p>
Human genome editing related research areas	<ul style="list-style-type: none"> Engineering cell-lines and organisms Therapeutic genome editing Screening (i.e. genome sequencing at/before birth) Large-scale population genomics sequencing Social and ethical issues pertaining to the technique / applications Language, culture and communications Practical and policy implications (i.e. for health service operations / system)
Human genome editing research themes : areas where genome editing has transformational potential for human health	<ul style="list-style-type: none"> Treating human diseases (cancer, rare and common genetic diseases) Preventing illnesses being passed from one generation to the next Assisted reproduction Preventing the spread of infectious diseases (e.g. zika and malaria) Drug screening Human 'enhancement'

This table represents a crude first stab at defining the territory. We believe that a representation of this nature is useful to anchor conversations about the topic.

A quick first activity at the workshop will be to 'road test' this representation with you and refine it.

In advance of the workshop, please consider (if you are working as a researcher):

- How helpful a representation is this? How could it be improved?
- How different might this look in 3 – 5 years time?

If you are involved in developing policy, which areas do you think will pose the greatest challenges, for instance:

- Sharing of genetic data, and consent issues
- Licensing of applications
- Reconfiguring health services etc

Taking stock of public engagement activity

What public engagement has already taken place, or is currently planned? What have we learned about 'what works'? Where are there specific challenges or issues to address?

3. Take stock of the public engagement that has been undertaken to date and the key lessons learned

It is widely recognised that sustained and expert public engagement is critical in areas of emerging science and technology. Without this investment, there are serious risks of science, policy and public opinion falling out of step. A key focus for this workshop will be to identify where this investment can best be made.

Funders of research in genome editing have already identified the vital role of public engagement:

Active early engagement with a wide range of global stakeholders will therefore be needed, which should include, but not be limited to, biomedical and social scientists, ethicists, healthcare professionals, research funders, regulators, affected patients and their families, and the wider public. Many of these considerations will not be unique to this specific technology, but will apply across a number of future developments in science for the benefit of health. [Genome editing in human cells – initial joint statement](#) (AMS, MMRC, CRUK, BBSRC, MC, Progress Educational Trust, Wellcome and Sanger Institute)

The Sciencewise programme works to develop public dialogues in priority areas. Arising from this workshop, we expect there to be some key opportunities identified which we will seek to act upon with relevant parties.

The [National Coordinating Centre for Public Engagement](#) (NCCPE) works to support the research community to develop more effective public engagement. We will also seek to capitalise on the intelligence gathered at the workshop to develop resources or programmes to enhance current activity.

In exploring the public engagement work to date, we think it is helpful to divide this work into two distinct types.

Much of the public engagement had been focussed on **helping the public to understand the science**. Often framed as a conversation with the public, the primary goal is to help the public understand what can be a bewildering and potentially confusing topic – one full of potential (to address seemingly intractable health issues) but also one that invites suspicion and distrust. We explore below what we have learned about how to have these conversations; what works; and where there is room for improvement.

The other type of public engagement is what is often termed ‘**public dialogue and deliberation**’: here we are talking about structured dialogues which are intended to elicit public views and to directly influence policy decisions.

We will look at each in turn.

Building public understanding of genome editing

An overview of current activity to support better public understanding of genome editing

Wellcome has funded the NCCPE and Wellcome Genome Campus to run a 12 month project to bring together those with experience of engaging (or supporting others to engage) the public in genome editing and related fields, to synthesize learning, create tools to be shared, and to encourage high quality public engagement. To date the team has invited people working in the field to identify key resources and to share future public engagement plans. The box below provides a summary of what was revealed.

An event was run in October 2017 to bring together 40 people working in the area to explore what was known about engaging the public with genome editing, and how the GEPES project could help to develop innovation and collective impact in the work. The event generated a set of recommended next steps which are currently being actioned.

Find our more: <https://www.publicengagement.ac.uk/nccpe-projects-and-services/nccpe-projects/genome-editing-public-engagement-synergy>

A snapshot of current public engagement activity



Audiences: the majority of engagement focuses on general public, school students, teachers, policy makers.



Topics that are being prioritised: DNA (basic background science), CRISPR, genome sequencing and other techniques, ethical and societal issues surrounding genome editing, embryos



Format of PE: there is a large number of events/exhibitions (i.e. public lectures, festival exhibits), schools workshops and visits. A number of organisations provide educational materials for schools (i.e. curriculum materials, practical activities), and some are conducting dialogues.

Location: often festivals, online, public lectures at learned societies, site visits.

Resources available: Policy and regulation guidance, PE Strategies and strategic guidance, videos explaining research/Genome editing, Data and associated guidance for schools, Conference notes and consultation responses, Audience insight, Websites including videos, classroom activities and guidance, Research repositories on ethics, Expert reactions to new research, Advisory groups, networks and coalitions.

Key Findings from the GEPES launch event

- 1. There is value in working together strategically**
Concerns were raised over a lack of joined up activity between organisations. It was suggested that an overarching strategy could help identify and fill gaps in activity/audiences engaged, whilst working towards a more coherent national conversation.
- 2. A snapshot of current activity is necessary to support strategic planning**
The GEPES programme has begun to a map of current and planned activity. It was agreed that the activity map should provide a snapshot of activities once a year. The activity map should not attempt to map everything, but key investments would be useful.
- 3. There is a need for effective resources to be developed and shared for use in Public Engagement, alongside a more consistent terminology**
The GEPES project aims to provide ‘how to’ guides to support practitioners and researchers to develop their engagement approach. The group endorsed this approach.
- 4. Common Evaluation Questions will enhance our audience understanding, and improve what we do**
- 5. Training to support researchers and science communicators needs to build confidence, and utilise the developed resources**
- 6. There is an appetite for national public engagement with genome editing programme**
Event attendees were keen to explore the potential of a national project framed on genome editing

Some lessons learned about how to help people understand the science and its implications

A number of challenges have been identified in helping the public to make sense of genome editing, for instance through the 'Basic Understanding of Genome Editing' project: <https://www.progress.org.uk/genomeediting>



BASIC UNDERSTANDING OF GENOME EDITING EXECUTIVE SUMMARY AND KEY RECOMMENDATIONS

Project led by Genetic Alliance UK and the Progress Educational Trust
Supported by the Wellcome Trust

September 2017

The 'Basic Understanding of Genome Editing' project was led by Genetic Alliance UK and the Progress Educational Trust (PET), and was funded by the Wellcome Trust. The project centred on a series of workshops and online engagement events held between January 2017 and May 2017, which explored what people think and know about genome editing and its implications. The project sought to incorporate participants' voices into the development of language and images around genome editing, and to empower participants to discuss genome editing's current uses and future potential

The report makes 8 recommendations

1. Use the term 'genome editing' exclusively. Do not use potentially confusing alternatives such as 'gene editing', 'genetic editing', 'genomic editing', 'genome engineering' or 'genetic modification'.
2. Before attempting to describe or discuss genome editing, ensure that your audience has some understanding of what a genome is. Explain this if necessary.
3. Prioritise explaining the use(s) of genome editing over explaining the mechanism(s) via which genome editing works. Deprioritise the term 'CRISPR' – do not use the term interchangeably with genome editing (as CRISPR is just one possible approach to genome editing), and think carefully about whether and when it is necessary to refer to CRISPR at all.
4. Explain genome editing as straightforwardly as possible, certainly in the first instance. Use simple analogies and metaphors – 'find and replace', 'copy and paste' and 'cut and paste' work well, and build on the fact that 'editing' is already something of a metaphor. Metaphors have their limitations, but they are useful in establishing basic understanding before attempting to go into greater detail.
5. When discussing uses of genome editing, distinguish clearly between: Human and other uses; current and future uses; research and treatment; uses that are currently permitted and uses which would require regulatory change. It may also be important to distinguish treatment from enhancement, but refrain from suggesting that there is a settled consensus on what this distinction means and where it lies (as that particular debate is ongoing).
6. When discussing a use of genome editing that relates to humans, take particular care to address whether or not it could (intentionally or inadvertently) affect the human germline – in other words, cause a heritable change to the genome.
7. Be prepared to have to differentiate between genome editing and genome sequencing and/or between genome editing and mitochondrial donation, as these are common areas of confusion. Having made it clear that these are different things, then bring the conversation back to genome editing.
8. Do not expect complete retention after one explanation of genome editing, no matter how well-received the explanation is. The message will need to be repeated multiple times, in order to achieve enduring comprehension.

Royal Society research into potential uses for genetic technologies

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



Findings Report
December 2017

Report Authors:
Anita van Mil, Henrietta Hopkins, Suzannah Kinsella

The Royal Society has been leading a [major programme on genetic technologies](#), exploring questions such as: What can genetic technologies be used for? What should genetic technologies be used for?

As part of this programme, they conducted research in 2017 to explore the range of views that individuals hold concerning which potential applications for genetic technologies should be developed, why, and under what conditions. The results of this research will inform their work on the future of genetic technologies' development and regulation. The research included a deliberative public dialogue followed by a nationally representative survey of the UK population.

Five conclusions were drawn from the process:

1. Cautious optimism for genetic technologies in society

There is a cautious optimism in society for genetic technologies and their uses. 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











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, 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.

CONT'D

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

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, 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:

- Publishing a Royal Society response to this report demonstrating that the voices of those involved, particularly dialogue participants, have been heard
- 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
- 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
- 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.

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

Some questions to explore at the workshop:

- How helpful do you think the recommendations of the GEPES project, the 'Basic Understanding of Genome Editing' and the Royal Society research are? Which would you prioritise?
- What other factors should be taken into account in seeking to support the public to engage with and make sense of the science?
- Do we need to commission more long-term research to better understand the impact of interventions over time and to help us understand what works?

Engaging the public in dialogue about genome editing

Engaging the public with controversial areas of emerging science and technology

In the nearly 15 years since it was established, Sciencewise has built up an extensive body of knowledge about how the public typically react to emerging technologies. [A review](#) conducted in 2012 identified the following responses. We can assume that most if not all of these will also apply to public responses to genome editing:



This review finds that there is a consistent set of views and responses from public participants across the dialogue projects. The eight most common responses being:

1. Conditional support for the area of research being discussed;
2. Desire to see equitable distribution of both potential benefits and potential risks;
3. Business participation in research process is welcomed. However, society as a whole rather than business should set public research agendas;
4. Desire to see research focused on clearly articulated societal needs;
5. Preference for targeting incremental solutions to societal challenges;
6. Valuing 'naturalness' – that is scepticism of the value of high-tech solutions to complex social and environmental problems;
7. Focus on value for money (both in terms of the research and the envisaged applications of research); and
8. Anticipatory regulation of emerging technologies should be considered simultaneously with research and innovation of these technologies.

To date, there has been little dialogue activity specifically focussed on genome editing. The next three slides summarise useful insights to inform the discussion.

Sciencewise review of approaches to public engagement with GM

Talking about GM: Approaches to Public and Stakeholder Engagement



Talking about GM: Approaches to Public and Stakeholder Engagement

A paper by the Sciencewise-ERC subgroup on GM dialogue September 2011

This 2011 paper provided a useful summary of public opinion about GM. Some of these findings could usefully be applied to Genome Editing

Public views

The work exploring public views reviewed here does not paint a simple picture of public opinion, the diversity of which is impossible to capture. There is no evidence of overwhelming intrinsic opposition to GM. Public concerns are conditional. They tend not to be expressed in terms of “yes” or “no” but in terms of “yes, but...” and “no, but...” Concerns can be described at different levels, ranging from those that are specific to GM technologies to those that are about the governance of science and innovation in general:

- 1. Safety** – The entry point for many people’s understanding of new technologies is the question of risk. Much of the public debate about GM food focused on this controversy to the exclusion of other issues. Public groups do indeed express concern about the potential hazards of GM food, but these concerns are the start of the discussion rather than the end.
- 2. Novelty** – The context for many people’s discussion of risk is the question of how new these new technologies are. GM aroused public suspicion with a familiar pattern in which the technologies’ benefits were advertised as brand new but risks were seen as conventional and well-understood. Clear and comprehensive labelling and independent information are consistently highlighted as essential.
- 3. Sustainability, uncertainty and ignorance** – People are clearly concerned that new interventions in complex ecosystems challenge scientific understanding. Do proponents of GM technologies know as much as they claim about environmental impacts, or are there areas of substantial ignorance that aren’t being acknowledged? The perceived „unnaturalness“ of GM technologies is one common manifestation of such concerns.
- 4. Socioeconomics** – GM technology is not just seen as an intervention into just the food chain, nor just the environment. Public dialogue exercises bring to the surface a recognition that GM technologies also present economic issues. Questions about intellectual property, patenting and the livelihoods of developing country farmers therefore become important.
- 5. Governance and regulation** – At the broadest level, people lack confidence in the ability of scientists, companies and governments to understand and regulate the myriad possible implications of new science and technology.

Uncertainty complicates how the public approaches the subject and encourages a default scepticism about the wisdom of accepting GM. The 'need' for GM was also questioned given the potential risks and the availability of other options to solve specific problems. The use of GM in the developing world is seen as a specific issue, although there were mixed views on the need for and value of GM in that context.

Genome editing technologies: the patient perspective



This [2016 report](#) by Genetic Alliance UK provides valuable insights into patient perspectives:

Executive summary

Patients are interested in genome editing technologies, and would like to learn more about them.

Two thirds of patient respondents had thought about the implications of genomics editing technologies, and over 80% were interested in finding out more about these technologies. Patients and families are open to engaging in conversations that will enable them to learn more about the potential of these technologies.

Patients welcome the use of genome editing technologies in research and clinical settings, but are clear that such uses should be limited to treating medical conditions not for the enhancement or alteration of physical or cognitive attributes of healthy people.

Respondents overwhelmingly support the use of genome editing technologies in research, where that research is focused on treating medical conditions. Respondents were equally welcoming of the use of genome editing technologies in a clinical setting, but again, a clear distinction was drawn between acceptable uses in a medical context, and the use of technologies to enhance physical attributes in healthy people, which was deemed unacceptable by most.

Patients call for multiple stakeholder approach two regulatory decisions to ensure ethical use of genome editing technologies, and want to be involved in this process.

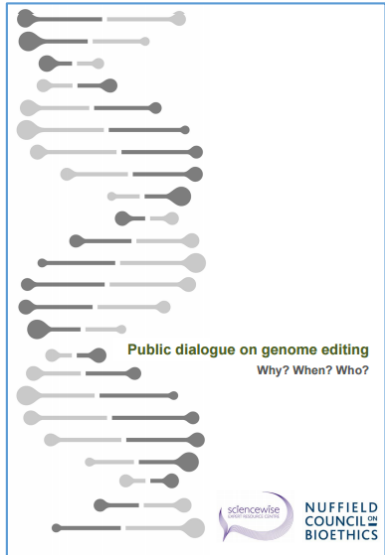
Patients want to have a say in the regulation of gene known editing technologies, but as part of a multi-stakeholder approach involving government, researchers and clinicians. Patients see the role of patient groups as important in representing their views.

Patients are clear that consent must be obtained in a way that ensures the recipient of any genome editing process understands the risks.

Most respondents see a need for clear consent guidelines in the administering of genome editing technologies in clinical settings. Most respondents feel that if such technologies were available to patients, they should only be offered via referral by a specialist clinician, and that it should be confirmed that patients understand the risks and benefits of the process being used.

Overall, patients feel the future of genome editing technologies offer more potential benefits than risks, if tightly regulated and used in the treatment of medical conditions.

Public dialogue on genome editing: why, when, who?



[This report](#) provides a really useful summary of recommendations from a 2016 workshop. The workshop brought together people with three distinctive kinds of interest in discussing genome editing: scientists and research funders who are involved in the developing the techniques and applying them to understand and manipulate living systems; policy makers who will have to set the conditions in which this takes place to protect and promote the public interest; and dialogue specialists who can offer advice on the different modes, benefits and limitations of public engagement.

The purpose of the workshop was to address three main questions:

1. What are the policy issues involving genome editing that are likely to have the greatest public salience?
2. What are the likely benefits and limitations of public dialogue in relation to the issues identified?
3. What are the possible timings and contexts for any public dialogue on the issues identified?

Various suggestions for dialogue-based activity were made, including:

“Dialogue about specific policy questions would be enabled by a background of **candid science communication** and public engagement on the part of all actors in the system. The alternative was to leave a vacuum that risked being filled by assumption, rumour and suspicion. The approach envisaged was a flowering of local, **micro-dialogues**, which need not be strategically coordinated, and which individuals and small groups with an interest in research would take responsibility for initiating. Participants agreed that assistance to research professionals in developing the skills and capacity to speak publicly about their work would be highly desirable. While researchers should be encouraged and supported to engage in such initiatives it would be a mistake to rely solely on them as other actors, from the commercial and third sectors, and policy roles, are also key players”.

The idea of a ‘**networked observatory**’ was also enthusiastically received:

“Participants were agreed on the need to take an active approach to anticipate the need for dialogue rather than waiting for a controversial issue to overtake and define the policy agenda. The discussion towards the end of the plenary session turned to how sensitivity and responsiveness could be brought to public policy. It was suggested that part of the answer to this might be to develop an appropriate early warning system. The fact that genome editing applications potentially cut across established organisational distinctions and divisions of policy responsibility led participants to discuss the desirability of a networked observatory, focussed on developments in genomic science with potential impact on public policy. This would benefit from operating across government, as well as its agencies and arm’s length bodies that have public or regulatory policy responsibilities, with input from industry and the third sector. The observatory would work to both to horizon scan for emerging areas in need of engagement and coordinate and synthesise the micro-dialogues. The need for networked information gathering and sharing is important as it is likely that many genome editing issues will have multiple policy owners (or none).”

Where next for public
engagement and genome editing
for human health?

4. Identify a strategic response to the above, agreeing how future public engagement activity might be better targeted and prioritised to address the opportunities and risks identified

To end the workshop, we are keen to return to the landscape we reviewed initially, and to the policy 'hot spots' that have been identified in the short to medium term.

We want to end by inviting you to consider the questions below:

Public understanding

- What's the minimum level of public understanding we need to ensure science, policy making and society don't get out of step over developments in this rapidly changing field?
- What should be priority actions to achieve this?
- Who should take responsibility, for what?

Public involvement and dialogue

- What are the critical policy and research 'hot spots' around which future dialogues should be focused?
- What form might these dialogues take?
- Who should take responsibility for ensuring these happen?

Domain	Focal points for investment and activity
Genome editing technologies	<ul style="list-style-type: none"> • Engineered nucleases <ul style="list-style-type: none"> ○ CRISPR/Cas9 (and derivatives) ○ ZFNs ○ TALENs • Recombinant adeno-associated virus (rAAV) • Homing endonucleases/ mega nucleases • Programmable base editing
Human genome editing technology applications	<p>Basic research Genome-editing research conducted on human cells, tissues, embryos, and gametes in the laboratory.</p> <p>Clinical research Therapy by editing in somatic cells Therapy by editing in germline cells</p>
Human genome editing related research areas	<ul style="list-style-type: none"> • Engineering cell-lines and organisms • Therapeutic genome editing • Screening (i.e. genome sequencing at/before birth) • Data analytics (i.e. large genome-size and population data) • Social and ethical issues pertaining to the technique / applications • Language, culture and communications • Practical and policy implications (i.e. for health service operations / system)
Human genome editing research themes: areas where genome editing has transformational potential for human health	<ul style="list-style-type: none"> • Treating human diseases (cancer, rare and common genetic diseases) • Preventing illnesses being passed from one generation to the next • Assisted reproduction • Preventing the spread of infectious diseases (e.g. Zika and malaria) • Drug screening • Human 'enhancement'