



National  
Co-ordinating  
Centre for  
Public Engagement



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# Genome Editing Public Engagement Synergy (GEPES)

## Final Report

### NCCPE GEPES Team

Acknowledgements: We would like to acknowledge the significant input from colleagues at the Wellcome Genome Campus. We would like to express our thanks to all of the people who contributed to the development of this report and the GEPES programme.

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## GENOME EDITING PUBLIC ENGAGEMENT SYNERGY (GEPES) FINAL REPORT

### INTRODUCTION

Whilst public engagement with science is viewed as increasingly important by policy makers, researchers, the wider STEM community, and the public; questions remain about how to engage people in controversial areas of science, particularly areas where the science is developing quickly. Genome editing, machine learning and autonomous vehicles are key examples of where there have been rapid advancements made in recent years that stand to radically shape the future. These advances may transform how we live our lives, helping us address some of the key challenges of our time. Therefore there is an urgent need to engage publics with these areas of research, ensuring that their development and use is responsible, informed by society, and beneficial to all.

The [National Forum for Public Engagement with STEM](#) were keen to explore how best to engage publics with emerging areas of science and technology. They conducted a light touch review of public engagement with six such areas. The findings illustrated that whilst there was some key strategic work taking place in [Machine Learning](#), activity on the whole was fragmented, and tended to be focused on inspiring and informing audiences.

Based on this review, in 2017 Wellcome commissioned a project to look specifically at public engagement with genome editing, to consider whether working on a very specific area of science could generate useful insights into wider questions about the role of public engagement in controversial and rapidly emerging areas of science. The NCCPE were successful in winning the tender for the call, and were awarded the contract for a pilot programme - the Genome Editing Public Engagement Synergy Programme ([GEPES](#)).

### GEPES AIMS AND ACTIVITIES

This pilot project sought to bring together all those with an interest or expertise in engaging the public with genome editing to share what they had learned about doing this well, develop useful resources to support others, and consider if and how they might work together in the future.

GEPES was facilitated through two symposia with participants with expertise of engaging the public or supporting others to engage the public with genome editing. In addition we convened an international symposium to share learning and perspectives across different countries tackling similar engagement issues. Working alongside the Wellcome Policy Group for Genome Editing and



partnerships with a range of organisations including the Wellcome Genome Campus, the GEPES project team developed the following outputs:

- A [comprehensive map](#) highlighting existing public engagement activity
- [Developing a learning framework](#) for reflecting on audiences and learning journeys
- A [draft framework](#) for the evaluation of public engagement with genome editing
- [Two training modules](#):
  - Engaging with controversial areas of science
  - Analogy training
- A [guide to](#) using analogies and metaphors.
- [Case studies](#) highlighting public engagement in practice.
- [Resource guide](#), drawing together key resources related to public engagement with genome editing.

In addition to these outputs we worked with the community of practitioners and key organisations to explore how we could pool efforts through sharing resources, leveraging different audiences in order to broaden reach and depth of engagement, and think more strategically about audience pathways through activity.

All the outputs and event reports can be found in full from the [GEPES website](#).

## KEY LEARNING

The programme brought together a community of practice involving organisations, and individuals committed to engaging the public with genome editing for human health. Through discussion, debate, and sharing practice from across UK and internationally, a number of learning points arose. First in relation to how you facilitate a community of practice around an emerging area of science, and second in relation to implications for public engagement.

### Facilitating a community of practice on public engagement with genome editing

1. **Appetite for community of practice:** There was significant interest from organisations and individuals interested in engaging the public with genome editing to come together, to share learning, and develop understanding. This led to support for the GEPES programme, and a desire from project participants to continue meeting together and sharing practice after the programme came to an end. The majority of ideas that emerged were delivered as outputs from the GEPES programme.

The majority of ideas that emerged from this community were tested and then translated into concrete outputs from the GEPES programme. One idea that emerged from the first event was the suggestion of a National Campaign, for example an annual awareness day focussed on



genome editing. In response to this we scoped what a national public engagement programme could look like, and used this to frame a consultation with delegates at the second event. Whilst there was interest in developing a national approach, there was no consensus about the purpose or content of such a programme, and no one who was willing to co-ordinate it. There was also a question about when a national approach could be useful or necessary.

2. **Defining the territory:** The project was focussed on genome editing on humans, relating to genome editing on human cells, as opposed to genome editing on plant or animal cells. The motivation behind this was to consider if focussing on one topic could help explore the wider issues relating to public engagement with controversial areas of rapidly developing science. However, the focus on genome editing on humans was at times problematic, raising questions about if and how publics are engaged with specific areas of science, and the boundaries of what is in and what is out of scope. Several groups argued that it would have been more helpful to either look at genomics as a whole; or to include genome editing of plants and animals – which also has impacts on human health. We subsequently expanded the terms of reference of the programme to account for these suggestions, focusing on genome editing for human health rather than on humans. This broader definition took into account research related to food systems, the environment and biodiversity for example.
3. **Engagement with genome editing is in its infancy:** There was an assumption at the start of the project that there would be a wealth of experience and expertise on engaging the public with genome editing. However our first call for evidence suggested that very few people focus their engagement so specifically; that the majority of engagement happens in schools; and that the work being done to help understand how publics relate to genome editing was under-utilised in practice.
4. **Researchers lacked confidence to engage the public:** The programme found that researchers can be reluctant to engage publics with controversial areas of science, or to engage with audiences whose interest lies in the potential applications of the research, its governance, wider ethical considerations, or other topics that researchers felt sat outside their domain expertise. Therefore support was necessary to help researchers develop the skills and confidence to engage well, as well as considering who else they could work with to develop their engagement approach. To help support this, the GEPES programme developed a training course to specifically address these issues.
5. **Evaluation is not straight forward:** There was an appetite for an evaluation standard, with a question bank of methodologically sound questions that can be used to understand the people you are engaging with, and to assess if and how your intervention has changed attitudes or understanding. Whilst there have been some successful examples of developing generic and high level evaluation frameworks (e.g. the [Generic Learning Outcomes \(GLOs\)](#)), this was challenging. Tensions arose from assumptions about what people need to know in order to engage with a particular topic, and if and how knowledge of specific facts about the science can



aid or hinder engagement for different contexts. The GEPES team worked with expert evaluator, Gene Rowe, to explore if and how a common question bank could be created to support evaluation of public engagement with genome editing. An evaluation framework for knowledge and attitudes to genome editing was developed, and piloted in practice.

6. **Motivations to engage:** A number of people participating in GEPES highlighted the importance of recognising the different learning journeys people might go through, for example through formal education; or as a patient; at a Science Museum; through the Media etc. and how these different intervention points might combine to shape and inform attitudes to science. Foregrounding these very different motivations (of engagers as well as the engaged) was an important opportunity to help the community of practice reflect on how and why they were working in the ways they did. Whilst this broad framework was outside the scope of the current project, we worked with Bella Starling and Niall Johnston, to explore the current literature of public understandings of genome editing, and to map out the potential motivations, interests, knowledges and values of the engagers and the engaged, to consider how these could be taken into account when planning activity. In addition, we encouraged the inclusion of questions about genome editing in the new Public Attitudes to Science survey.
7. **International perspectives:** The project benefitted from engaging with people from other countries, enabling an exploration of the challenges faced within different contexts, sharing learning, and exploring the need for international governance of areas of science that transcend national boundaries. It was clear from this work that national decisions about genome editing affect us all, wherever we live.

## BROADER IMPLICATIONS FOR PUBLIC ENGAGEMENT

The aim of the GEPES programme was to inform our understanding of how we better equip researchers, volunteers and other professionals to engage the public with other areas of controversial and rapidly emerging science.

1. **Culture Change.** Whilst the GEPES programme brought together new people to discuss public engagement, it was notable how many of the challenges and opportunities are relevant to all engagement with research. Most notably, the need for a culture of support for public engagement within research organisations was highlighted in the discussions, alongside a recognition that without this institutional support it was difficult for researchers to develop their engagement work and to do it well.
2. **Quality engagement.** The programme highlighted what is already known about high quality engagement. For example, we recognise that it is important to be clear about who you are hoping to engage with and why. Understanding potential motivations, interests and needs of participants is critical in designing activities, and where possible participants should be



involved in designing the approaches. It is important to use evaluation strategically to develop and evidence your approach. Context is important, as is researching who else is working in the areas you are interested in, to avoid duplication, provide potential for collaboration, and to learn from others' approaches. The importance of working with intermediaries to help shape debate (e.g. policy makers) or to reach specific public groups such as patients, was emphasised in the discussions that took place.

- 3. Work in teams.** The research indicated that publics were not just interested in discussing the science. Quite often there is interest in business models, funding choices, ethical considerations of research application and development, and the overall politics and power dynamics relating to science and its use. Conversations that took place in these areas were often considered out of the domain of the scientist as a professional. However closing the conversations down may have a negative impact on people's overall experience of an event or intervention. We found that researchers can benefit from support to help them develop strategies to facilitate conversations whilst remaining authentic about their areas of expertise. This support can come in the form of training and development, but can also come in the form of inter-disciplinary support. Working with social scientists, ethicists, or artists by way of an example, has been proven to really help support debates that transcend the science into these broader areas such as application, human existence and politics. In addition, recognising that researchers don't need to have the answer for everything, and that by being clear on the boundaries of their expertise for example through signalling when they are answering as an expert or when they are answering on a more personal level – or finding ways to bring in the audience and listen to their views on these more personal topics - can really help scientists engage effectively.
- 4. Understand the different motivations you bring to this work.** Clearly the motivations for engaging will affect the engagement activity. Engagement purposes might range from providing inspiration and learning opportunities; consulting with patients who have a specific condition; or exploring the ethical implications of an area of research for example.

In addition to the purposes of the intervention, the different motivations held by the engager will shape the approaches that are taken. Therefore the more these motivations are brought into consciousness and reflected upon critically, the more targeted and meaningful our interactions with the public can be. The 'developing a learning framework for reflecting on audiences and learning journeys' resource developed as part of the GEPES project begins to unpick some of these potential motivations, values, and attitudes.

- 5. Understand the different motivations other people bring.** When addressing areas of controversial science, it is important to remember that people may come to it from a variety of reasons. For example, they may be curious to find out about a new area of science; stumble across an activity at a science fair and be curious to get involved; they may be interested in how the science might address a specific medical condition they or a family



member have; or may be concerned about implications arising from the science. Given these different motivations, people may engage in different ways. For example, if you are working with patient groups some people may not be interested in the science, but the impact that the science can have on their lives or the lives of others; if you are doing a science activity at a science festival, people may engage because they want to have an enjoyable day out.

- 6. Share learning across different sites of practice.** Many professional communities are involved in engaging the public with genome editing. This includes, teachers, healthcare professionals, and policy makers. The GEPES project demonstrated that there is untapped potential that can be unlocked through working more meaningfully across professional silos. The 'developing a learning framework for reflecting on audiences and learning journeys' resource provided a framework which could be used for this purpose, helping people to step back and consider their own and others' motivations for engagement and the assumptions underpinning their interventions. This is a model which could be usefully applied to other areas of emerging science.
- 7. Think carefully about language.** As with other areas of science, genome editing can be complex to describe. New terms, metaphors and analogies are therefore created to help explain the science. These are often adopted and can become widespread. These terms and analogies can also lead to misunderstandings, as illustrated by a study by [The Progress Educational Trust and Genetic Alliance UK](#) describing how genome editing is explained in the media. Therefore it is important to choose your metaphors wisely. The GEPES project developed a guide to the pros and cons of the widely used metaphors, and tested these out in practice.

The guide explores how language and framings also have ethical implications. For example, the potential of genome editing to make a difference to human health is often coupled with language such as 'preventing', 'screening', 'enhancing' and 'treating'. This language can raise expectations as to the potential impact of the science, which are not realistic, and the use of these terms can be controversial, underpinned by assumptions of what it means to be human. Amongst those involved in the GEPES project there was a consensus about having a common language to describe genome editing that could be adopted by all those seeking to engage the public with the topic.

- 8. Surface assumptions about learning and the purposes of interventions.** In addition to the challenges around language, it was clear from our symposia and desk research that researchers and those supporting them often work with specific ideas of how people learn, how you engage with them, and how you measure change. For example, some advocate that the public need to understand basic genomics, screening and diagnostics before they can understand genome editing whereas others thought it was possible to engage people in debate without prior knowledge. Many involved in engaging the public were informed about assumptions about how people learn and what knowledge is needed in order to engage



meaningfully with genome editing. It is important that these assumptions are surfaced and explored, and GEPES provided a space in which this kind of reflection flourished.

9. **Governance.** Genome editing is a newly developing area of science, and there are concerns that the science outpaces our ability to develop regulatory systems that support and manage it ethically. Genome-editing technologies challenge existing governance systems and their capacity to determine whether there are genetic alterations that are insufficiently justified, too risky, or too socially disruptive to be pursued at any given time. Science governance models, of which public engagement can form a part, are influenced greatly by the institutional arrangements within one given country. Our approaches can range from more adaptive or responsive models, focusing on dialogue and involvement, with a commitment to incorporate and adapt to new information as it becomes available; through to efforts that are more explicitly focused on reducing the ‘trust gap’ so that new technologies become more publicly acceptable. Issues around governance therefore need to be surfaced and debated in the context of any project working in areas of controversial science. Consideration needs to be given to how the engagement activities being undertaken can contribute to evolving national policy. The GEPES approach provides a useful platform to connect publics, researchers, intermediaries and policy makers.

## CLOSING SUMMARY

Genome editing is one of several new areas of science that is moving rapidly and has potential impacts on people’s lives in a way that sets it apart from many other forms of scientific advancement. It brings specific implications for public engagement, touching as it does on human rights issues such as identity, dignity, justice and equity, and embodying uncertainties about risk, the pace of change, potential impacts and unintended consequences, which can subsequently bring societal divisions, unequal access and social problems into public dialogue or activity. It also poses significant challenges for people designing engagement activities as the underpinning science is complex and hard to grasp. Establishing how much of the science people need to understand in order to engage in more expansive debates about the ethical and social implications is a critical challenge.

The GEPES programme highlighted the need for a range of resources to support the sector to engage publics with genome editing, including a resource directory; case studies; training; the ‘developing a learning framework for reflecting on audiences and learning journeys’ resource; a draft evaluation framework; and a guide for use of metaphors and analogies. These resources have been created by the GEPES participants, and are available to all, supporting more people to think through how best to engage the public with their work.

The programme also showed strong support for bringing together a core group of organisations and individuals working in this space to – (i) Share what’s happening, make connections, develop more effective interventions, share learning and align work to maximise efficiency, reach and impact; (ii)



Increase collaboration over areas of joint interest including opportunities to fill identified gaps (including gaps in geographical coverage; audiences; engagement purposes or approaches); (iii) Share effective practice with the host of stakeholders operating in this area, including researchers, engagement brokers, policy makers and funders, healthcare practitioners and patient groups and (iv) Develop and deepen broader networks and relationships with a wider group of stakeholders, organisations and individuals.

The original challenge set by Wellcome for the GEPES project was to explore whether working on a very specific area of science could generate useful insights into some of the wider questions about the role of public engagement in controversial and rapidly emerging areas of science. The project has demonstrated that this is possible. It is clear that many of the challenges GEPES identified and addressed are generic to any area of emerging science and technology - including language and framing; cultural support for public engagement within research organisations; values and motivations; and the need to develop effective practice relevant to the purpose of the engagement, and the people engaged. Many of the tools and approaches which emerged from the GEPES project could be re-purposed and applied in other areas of emerging science. At the same time, the project has demonstrated the value and importance of building communities of practice around quite tightly defined areas of science – like genome editing – as the subtleties and complexities inherent in these require deep and nuanced consideration, and the development of very targeted tools and resources pertinent to the area.

There would be real value in research funders considering how to ensure this kind of strategic support is made available to all researchers. One model could be to develop the idea of a **Collaboratory for Genome Editing**, building on [Simon Burall's Nature article: 'Rethink public engagement for gene editing'](#) in which an 'observatory' is proposed. His model focuses on enabling the sharing of practice and resource across consortia of organisations interlinking networks and respective knowledge of specific audience groups (for example, as members of farmer's unions, parent-toddler groups through to activist organisations). The participants in GEPES recognised the value of coming together in this type of forum, and the project has demonstrated how such observatories might work in practice.



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