



National
Co-ordinating
Centre for
Public Engagement

Genome Editing Resources

Genome Editing Public Engagement Synergy (GEPES)

Working Document, January 2018

GEPES project team

stephanie.todd@uwe.ac.uk

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About this document

This document pulls together a collection of resources that have been suggested by researchers and other professionals working to engage the public with Genome Editing. The document is divided into the following sections:

- **Activity resources** – tools and ideas for public engagement activities
- **Public talks, seminars and film** – a collection of TEDx talks and presentations/videos about Genome Editing and its applications
- **Dedicated websites** – suggestions of websites which act as resource banks or records of national activity.
- **Online courses and training** – training for researchers and professionals on engaging the public with genome editing.
- **Publications** - A collection of useful reports including those focusing on public engagement practice, ethics, genome editing research and governance.
- **Evaluations** – A body of evaluation reports from national programmes

We will be updating this document throughout the GEPES project, therefore if you have additions to make, please contact the project lead: Stephanie Todd on Stephanie.Todd@uwe.ac.uk

Activity resources

A collection of resources that can help you develop activities to engage the public with Genome Editing.

Inspiring: *Stimulating curiosity and learning about the science*

DNA Origami

This hands-on activity allows you to create your own paper model of a DNA double helix.

<https://www.yourgenome.org/activities/origami-dna>. It was used at the Summer Science Exhibition in 2017 and provides everything you need to know to build your own DNA model out of paper. If you like this, you may also like this [activity pack](#) from the Royal Society which includes a wide range of activities on the structure of DNA including crosswords, colouring in, and crafts.

Hands on DNA, Association for Science and Discovery Centres

Hands-on DNA was a national project working with science centres, museums and universities across the country which allowed students to get hands-on experience doing molecular biology experiments. The website for the project contains training and activities resources.

<https://www.sciencecentres.org.uk/projects/hands-dna/>

Scientific scissors resources, Biochemical Society

Scientific Scissors. The activity is all about Genome Editing – What is it? How does it work? What can we do with it? What *should* we do with it? Why is it important? The aim is to start conversations about new technologies and give people the opportunity to ask questions whilst engaging with the ethical issues involved. See the website for more details:

<https://biochemicalsociety.wordpress.com/2017/04/05/scientific-scissors-the-first-cut/> The resources can be downloaded here:

<http://www.biochemistry.org/Education/PublicEngagement.aspx>

Consulting: *Consultation and dialogue to elicit public attitudes and views*

Review of Research Councils UK dialogues, Involve

[Research Councils UK](#) (RCUK) commissioned Involve to conduct a review of RCUK dialogue and consultation exercises in order to identify what could be learnt more generally about public perspectives on emerging science and technology. The following pages provide findings from the review alongside guidance for research council staff who are involved, will be involved, or are interested in designing and delivering public dialogues.

<https://www.involve.org.uk/2014/01/03/review-of-research-councils-uk-dialogues/>

Meet the Gene Machine, UWE

Meet the Gene Machine was a lively drama and discussion event designed to raise awareness of the ethical implications raised by advances in medical genetics. The project was delivered nationally between October 2006 and March 2008 funded by Wellcome Trust. The project website

pulls together resources to help you deliver similar activities, a continuing professional development workshop for teachers and evaluation resources. Find out more here:

<http://www1.uwe.ac.uk/research/sciencecommunicationunit/projecthighlights/meetthegenemachine.aspx>

Your DNA, your Say, Wellcome Genome Campus

Gathering attitudes towards DNA and Big Data (Genomic Data Sharing). This is a survey about your online health data and how it might be used by others. Using film and surveys to elicit public views. Visit the website for more details: www.yourdnayoursay.org

Collaborating: *Enhancing governance or conduct of science*

Patient and Public Involvement and Engagement in Research, Central Manchester University

This booklet has been created to support researchers based at CMFT with public involvement and engagement activities. Biomedical research can work with the public in many different ways. In this booklet, we aim to highlight the benefits of researchers listening to the public to help inform and influence research and of raising awareness and building stronger relationships with the public around biomedical research.

<https://research.cmft.nhs.uk/wp-content/uploads/2015/05/cmft-ppie-guide-for-researchersfinal.pdf>

Public talks, seminars and films

Helen Sang, why do we need GM chickens, TEDx Glasgow - Shared by Nicola Stock from the Roslin Institute UK.

Over 50 billion chickens are hatched globally every year and soon poultry meat will become the most popular meat consumed in the world. If we are to manage the predicted increase in consumption, due to the increase in population and increase in wealth, we need to consider using all the tools available to us to improve the genetics of chickens and other farmed animals.

<https://www.youtube.com/watch?v=DUbgrh5otWs>

International Summit on Gene Editing – A Global Discussion – National Academies of Science and Engineering

A major component of the National Academy of Sciences and the National Academy of Medicine's Human Gene-Editing Initiative is an international summit that took place December 1-3, 2015, in Washington, D.C. Co-hosted with the Chinese Academy of Sciences and the U.K.'s Royal Society, the summit convened experts from around the world to discuss the scientific, ethical, and governance issues associated with human gene-editing research.

<http://nationalacademies.org/gene-editing/Gene-Edit-Summit/>

What is gene editing and how does it work? Royal Society

The Royal Society in conjunction with the Wellcome Trust produced a short animation explaining how gene editing works and raising some of its possible ethical and societal implications.

<https://www.youtube.com/user/RoyalSociety>

Resource websites

EuroStemCell

EuroStemCell is here to help European citizens make sense of stem cells. We provide independent, expert-reviewed information and road-tested educational resources on stem cells and their impact on society. More than 100 stem cell educational resources and teaching tools, fully catalogued. Ideal for teachers, science centres and museums, scientists doing outreach and others.

<http://www.eurostemcell.org>

Genomics England

Genomics England was established to support the 100,000 genomes project. The project will sequence 100,000 genomes from around 70,000 people. Participants are NHS patients with a rare disease, plus their families, and patients with cancer. Our library contains a wide array of policies, documents and resources related to the project.

<https://genomicsengland.co.uk/library-and-resources/>

Inspiring the next generation of researchers, MRC Human Genetics Unit – Medical Research Council

Staff and researchers from the MRC Human Genetics Unit are working with the lead biology teachers for Edinburgh and their colleagues to create a real data resource to allow students to explore genetic and phenotypic data as part of their Scottish Qualifications Authority [Nat5](#) or [Higher Biology](#) Assignment.

<http://www.ed.ac.uk/mrc-human-genetics-unit/public-events-resources>

Modern genetics for schools, Nowgen

Modern genetics promises much in relation to our health. The Nowgen Schools Genomics Programme worked to help equip young people with the necessary skills and understanding to assess the real potential of genomics and how best to make informed decisions about future healthcare. Our website contains a range of teacher and student resources, including activities, exam questions and case studies that can be used in teaching.

<http://www.genomicsforschools.org/projects/nsgp/about/>

Society and Ethics research from the Wellcome Genome Campus

We are the Society and Ethics Research Group, Connecting Science at the Wellcome Genome Campus in Cambridge, UK. We are a group of academics working in a non-profit research institute, who explore the ethical, legal and social issues raised by genomics. Our website contains a catalogue of all our work including journal articles, project pages and teaching resources.

www.wellcomegenomecampus.org/societyandethics

Your Genome – Wellcome Genome Campus

Website to engage public audiences with genomics and biodata through accessible content including articles, videos, animations and classroom activities.

www.yourgenome.org

Online courses

Consent and ethics online course – suggested by Wellcome Genome Campus

This module has been developed for healthcare professionals working in NHS England Genomic Medicine Centres and their local delivery partners who will undertake the consent conversation with potential participants interested in joining the 100,000 Genomes Project.

<https://www.genomicseducation.hee.nhs.uk/courses/courses/consent-ethics/>

Reports

A collection of useful reports including those focusing on public engagement practice, ethics, genome editing research and governance.

A new pathway for the regulation and governance of health research, Academy of Medical Sciences

The report was prepared by a working group, chaired by Professor Sir Michael Rawlins FMedSci, convened in response to an invitation from Government to review the regulation and governance of UK health research involving human participants, their tissue or their data. The report proposes four key principles that should underpin the regulation and governance framework around health research in the UK.

<https://acmedsci.ac.uk/policy/policy-projects/a-new-pathway-for-the-regulation-and-governance-of-health-research>

Annual report of the chief medical officer – 2016: Generation Genome

Key report providing an overview of Genome Editing research potential opportunities and challenges.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/631043/CMO_annual_report_generation_genome.pdf

Basic understanding of genome editing: the report - Genetic Alliance UK and The Progress Educational Trust

The report of the project's findings contains several recommendations aimed at people or organisations wishing to discuss genome editing in public.

<https://www.progress.org.uk/genomeediting>

Earning Trust: Public Engagement and Patient Involvement Strategy 2015 – 17, Genomics England

This document outlines the Genomics England strategy to build trust and public confidence in the 100,000 Genomes Project and in the security and privacy of its data.

<https://www.genomicsengland.co.uk/about-genomics-england/how-we-work/patient-and-public-involvement/> - see PDF at bottom of page

Explore 18 questions about genetically modified (GM) plants – Royal Society

The Royal Society commissioned [Ipsos MORI](#) to find out what people want to know about GM plants, and then drew on a panel of expert, independent scientists to answer your questions.

<https://royalsociety.org/topics-policy/projects/gm-plants/>

From Three-Person IVF to Genome Editing: The Science and Ethics of Engineering the Embryo - Progress Educational Trust

Event notes and highlight video from the UK's first public conference on genome editing in December 2015 with a keynote speech by the Government's Chief Scientific Adviser.

<http://www.progress.org.uk/conference2015>

Genomics and genome-editing: future lines of enquiry – 16th Report of Session 2016-17 – House of Commons Science and Technology Committee

Inquiry into Genomics and genome editing in November 2016, calling for evidence on the impact of these emerging scientific fields on human health, plants, animals and ecosystems.

<https://publications.parliament.uk/pa/cm201617/cmselect/cmsctech/854/854.pdf>

Genome Editing: An Ethical Review, Nuffield Council on Bioethics

This report aims to identify and define ethical questions relating to developments in genome editing research and highlights the nature of the ethical questions raised, exploring how they might most suitably be addressed.

<http://nuffieldbioethics.org/project/genome-editing>

Genome Editing: Scientific opportunities, public interests and policy options in the EU – European Academies Science Advisory Council

A report by the European Academies' Science Advisory Council on genome editing gives advice to European policy-makers on ground-breaking research involving genome editing and plants, animals, microbes and patients.

<http://www.easac.eu/home/press-releases/detail-view/article/new-easac-re.html>

House of Commons Science and Technology Committee Inquiry into Genomics and Genome Editing

This website contains all the responses to the HoC inquiry. The committee addressed a wide range of issues including impacts, regulation, ethical concerns and investment in infrastructure and skills.

<https://www.parliament.uk/business/committees/committees-a-z/commons-select/science-and-technology-committee/inquiries/parliament-2015/inquiry2/publications/>

Innovation: Managing Risk, Not Avoiding It

The first annual report of the Government Chief Scientific Adviser (GCSA), Sir Mark Walport, looks at approaches to risk in the context of innovation. The supporting evidence contains the views of leading experts looking at risk and uncertainty from a wide range of perspectives, including: social, psychological, industrial and financial.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/381905/14-1190a-innovation-managing-risk-report.pdf

Interim survey results on genome editing

Researchers working with What Is Biotechnology are running a pilot survey to gather people's views on this new technology. To date the survey has attracted feedback from 567 respondents and 1741 individual comments. This page contains a summary of the interim feedback from respondents.

<http://www.whatisbiotechnology.org/survey/overview/670a773b/8617c342>

Potential and risks of recent developments in biotechnology, speech by Venki Ramakrishnan, President of the Royal Society

This speech given to the American Association for the Advancement of Science sets the scene for developments in genetic technologies within the context of our long history of adapting biology through cross breeding of animals and plants. It unpacks the risks presented and the role of public debate and effective regulatory systems in helping shape the vision of the science.

<https://royalsociety.org/news/2017/02/venki-ramakrishnan-aaas-genetic-technologies/>

Public dialogue on genome editing Why? When? Who? – Nuffield Council on Bio-ethics and Science Wise

Report of a workshop on public dialogue for genome editing. The workshop was intended to focus specifically on exploring the potential role of *public dialogue for policy*, however the discussion extended to a spectrum of interactions between different societal groups, and reflecting on the current state and directions of genome editing science and technology, and the public policy and regulatory measures in place.

<https://nuffieldbioethics.org/wp-content/uploads/public-dialogue-on-genome-editing-workshop-report.pdf>

Talking about GM: Approaches to Public and Stakeholder Engagement – Sciencewise

Summarises the lessons learned from the short history of public dialogue exercises about genetically modified crops and food.

<http://www.sciencewise-erc.org.uk/cms/assets/Uploads/Talking-about-GM.pdf>

The Genomics Conversation (2016-2017), Genomics England

The Genomics Conversation was a year-long programme of activities led by Genomics England in 2016. The aim was to engage the public and relevant stakeholders in key topics relating to genomic medicine. The Genomics Conversation rolled out a broad range of activities, including debates, discussions, presentations, and outreach through social and traditional media.

<https://www.genomicsengland.co.uk/?wpdmdl=10840>

The scientific and regulatory landscape for human genome editing across the EU, Academy of Medical Sciences

In April 2015, the AMS together with the Federation of European Academies of Medicine (FEAM) and the French National Academy of Medicine hosted a European meeting to explore the scientific and regulatory landscape for human genome editing across the EU. The resulting report (and background document developed ahead of the meeting) is available from this link.

<https://acmedsci.ac.uk/policy/policy-projects/genome-editing>

UK Science Sector Coalition (UKBSC) – Royal Society of Biology

The UK Bioscience Sector Coalition (UKBSC) works as a “joined up voice” for UK bioscience stakeholders in the UK. The Coalition represents organisations, and reflects the perspective of academia, industry, small and medium enterprises, charities and other research funders, as well as patient and medical groups. It came together in response to the recognised need for communication and coordination among the main sector groups involved with animal science. Part of the activity of this group involves regular discussions on public affairs in relation to aspects of animal research involving the bioscience community.

<https://www.rsb.org.uk/policy/groups-and-committees/asg/asg-membership/current-activities>

Wellcome Monitor – Wellcome Trust

Public views on Medical research: survey explores the public's thoughts on medical research, science and health. Every three years we survey hundreds of people across the UK.

<https://wellcome.ac.uk/what-we-do/our-work/public-views-medical-research>

Evaluation

Gene Zone Report – March 2015: Provided by Shane McCracken, Mangorolla CIC

The Genes Zone was one of the most focused zones during the March event, with many discussions on the topics of genetics and DNA. A very high proportion of students (93%) were active on the site, the number of comments submitted was above average, and the ratio of approved questions to those submitted was high at 56%. The scientists were mostly excellent in attending chats, with nearly all the chats including at least three scientists.

<https://about.imascientist.org.uk/2015/genes-zone-report-march-2015/>

Genomics Zone Report – March 2017: Provided by Mangorolla CIC – Shane McCracken

The Genomics Zone was a themed zone funded by Genentech and Human Longevity, Inc. The zone featured scientists working on a range of genomics related topics from genetic diseases in children to cancer. The zone had 329 participating students from 13 schools. Class sizes ranged from 5 to over 30 students across grades 4 to 11. Most of the classes had two live chats with the scientists with more live chats taking place in the first week than the second.

<https://genomicsm17.imascientist.us/2017/05/06/genomics-zone-report-march-2017/>

Hands on DNA, Association for Science and Discovery Centres, suggested by Penny Fidler

Hands-on DNA was a national project working with science centres, museums and universities across the country which allowed students to get hands-on experience doing molecular biology experiments. Full details of the evaluation results can be found in the [summary evaluation report](#), written by Ben Gammon, the independent consultant who carried out the evaluation work on the project.