# Overview public dialogue project



# Public Dialogue Aims



- 1. Explore public attitudes regarding research using genome editing
- 2. Understand when and how to engage audiences with disruptive technologies
- Understand how public engagement
  strategies might differ between
- •.countries



### Public Dialogue Process

MAX DELBRUCK CENTER FOR MOLECULAR MEDICINE IN THE HELMHOLTZ ASSOCIATION



Method 1,5 days reconvened event (30 citizens)

Emilia Tikka

Workflow

**ORION partners** 

**Advisory Group** 

**Review Group** 

**Ipsos MORI** 

**Stakeholders** 

**Events w public** 



# Structure public events

- Biology quiz
- GE video
- Table discussions
- Case studies fundamental research
- Case study future uses: Medical uses / non-medical uses / animals / plants
- Science art discussion on possible future applications of research





# Public dialogue findings

- UK

**Emma Martinez Sanchez** 

Public Engagement ORION Project Officer



# Key societal challenges





## Public attitudes genome editing

	Strong support for basic research to help ensure the realisation of GE potential benefits
Initial Reactions	There was great uncertainty about current and future uses (applications) of GE
	One of the central questions was around the motivation of scientists undertaking the research
	GE seen as having great potential to address issues related to health, wellbeing, and food production
Hopes	In the case of health, it was expected that would be used to reduce suffering (life-threatening conditions)
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<u>() (@}}+</u> 4	Uncertainty about unintended negative consequences
Concerns	Rogue uses / missuses of the technology
	Lack of accessibility leading to social inequality, exclusion; lack of diversity
Trade-offs	Mechanism to ensure public / patient voices inform decisions around its use
	Effective international regulation to ensure deliver fair and ethical outcomes
	Guiding principles: of avoiding harm and suffering, and protecting social justice, human rights, fairness and equity





### **Babraham Institute Research Case Studies**

Basic biology research with an emphasis on healthy ageing through the human lifecycle

#### Signalling

PI3K proteins control cellular growth, reproduction, jobs and even lifespan – all factors for maintaining our health as we age.

Institute scientists edit the genome of model organisms to study new proteins from the PI3K pathway. What is the effect in mice when a protein no longer works?

#### **Epigenetics**

External factors can affect how genes work by tagging certain chemical groups to the DNA sequence.

Known as 'epigenetics marks', these chemical tags determine which DNA part can be read.

Institute scientists use genome editing to study how age and diet changes can affect epigenetic marks and if these are inherited.

#### Immunology

Our immune system declines with age.

We produce less antibodies, our immune response against pathogens is less robust and vaccines do not work as effectively.

Institute scientists use genome editing to study what causes our immune system to decline as we age.







### **Attitudes Babraham Institute research**

#### Signalling

- Exploratory research valued, in particular on the role of animal research, to minimise safety risks
- Possible societal impact of Institute research (slow down age-related health decline) on National Health System

#### **Epigenetics**

- Difficulty in understanding research goal due to technical jargon ('epigenetic', 'marks')
- Positive attitudes towards the preventative role of germline editing whilst conflicting with the lack of personal consent, consequences of unintended effects, and reducing human diversity
- Appetite for Institute scientist to provide information about science-backed health choices (e.g. effect of environmental factors and diet)

#### Immunology

- Attitudes related the societal benefit (increased health span) and its impact (overpopulation, accessibility, effectiveness for public health services) rather than over the aim of the research
- Request for governance to consider ethical implications (accessibility of treatments, cost/benefit analysis, freedom of choice over life and death)
- Appetite for Institute scientists to provide information about science-backed health choices











### **Conclusions Babraham Institute**

Limited understanding of basic research aim

Struggle to understand case studies and technology role within

Attitudes toward technology uses based on real-world applications

Institute scientists to share learnings about factors influencing health











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#### Thank you for your attention!

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