

## Appendix 1. Stakeholders consulted

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The following people were either interviewed via telephone or face-to-face (for vox pop filming) in the scoping and preparation phase of the public dialogue.

Name	Title	Organisation
Robin Lovell-Badge Contact Group Chair	Group Leader and Head of Stem Cell Biology and Developmental Genetics Laboratory	The Crick Institute
Kay Davies	Dr Lee's Professor of Anatomy; Director, MRC Functional Genomics Unit; Associate Head (Development, Impact and Equality) of the Medical Sciences Division	Oxford University
Ottoline Leyser	Professor of Plant Development and Director of the Sainsbury Laboratory	University of Cambridge
Dale Sanders	Director	John Innes Centre
Helen Sang	Personal Chair in Vertebrate Molecular Development	Roslin Institute
Bill Adams	Moran Professor of Conservation and Development at the Department of Geography	University of Cambridge
Austin Burt	Professor of Evolutionary Genetics	Imperial College London
Paul Freemont	Chair in Protein Crystallography	Imperial College London
Roderick Flower	Professor of Biochemical Pharmacology	William Harvey Research Institute, Queen Mary, University of London
Katherine Littler	Senior Policy Adviser	Wellcome Trust
Nick Pidgeon	Professor of Environmental Psychology	University of Cardiff
Patrick Holden	Founding Director	Sustainable Food Trust
Sarah Chan	Chancellor's Fellow	Usher Institute for Population Health Sciences and Informatics University of Edinburgh

## Appendix 2. Recruitment specification

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*Client:* The Royal Society

*Research theme:* Genetic Technologies

*Dialogue contractor:* Hopkins Van Mil: Creating Connections Ltd

### Aims:

The aims of the dialogue included:

- Exploring commonalities and differences in attitudes depending on applications and the source of the change introduced
- Identifying the problems that people feel genetic technologies are well placed to solve as well as the areas in which they would prefer greater emphasis be put on other solutions
- Identifying the frames and contexts that moderate the public acceptability of developing UK research into genetic technologies, e.g. UK competitive advantage, individual and collective welfare improvement, and environmental improvement
- Identifying who is trusted to work on particular technologies or applications, why, and with what implications, e.g. public vs. private researchers, for profit vs. not-for-profit commercial organisations.

The methodology will be 2 workshops in 3 locations for which participants will be recruited. The purpose of this document is to give the framework through which the fieldwork team will develop the detailed schedule and screener for recruitment. These will be approved by the Project Team via HVM before being used in the field for recruitment.

The dialogue will involve recruiting up to 30 (for 28) people, broadly representative of the population in terms of age, gender, life stage, social grade/ household income, geography and ethnicity. We will be gaining informed consent from participants in terms which comply with the DPA 1998 and will allow identifiable data to be transferred and stored securely by the commissioning body for future research and/or dialogue purposes. HVM is registered as a data controller with the Information Commissioner's Office no: Z2969274.

### Recruitment summary:

- Total number of workshops 6
- 3 recruitment exercises as follows:

Location	Dates	Focus
Norwich Venue tbc	R1: Tues 12/09/17 R2: Sat 07/10/17	The uses of genetic technologies in plants and microorganisms, including as sources of food, medical compounds, energy or raw materials.
London Venue tbc	R1: Wed 13/09/17 R2: Fri 29/09/17	Near to medium-term future (0 – 10 years from the present) scenarios for the uses of genetic technologies in 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 Venue tbc	R1: Thurs 21/09/17 R2: Sat 14/10/17	The uses of genetic technologies in animals, including animals as pests, sources of food, companions and wild creatures.

- All participants must commit to attending *both* workshops

- R1 workshops begin with registration at 5.45pm and end by 9.15pm
- R2 workshops begin with registration at 9.45 and end by 4pm
- Respondents will be asked to review some very short written/ visual material before participation
- Incentive: £160 for attendance at 2 workshops (£60 paid at first session, £100 paid at the end of the second session)

**Screener to include:**

<b>Criteria</b>	<b>Target</b>
Gender	50% identifying as male / female
Age	Good age distribution across age groups from every adult life stage
Ethnicity	An appropriate proportion of black and minority ethnic participants in line with 2011 census data for each recruitment area.
Life stage	A broad range of life stages from students, young professionals, raising young children to empty nesters and those who are retired (20% sample from each category)
Current working status and type	A range of people who are employed (part-time/ fulltime/ self-employed) and unemployed, plus those who are retired.
Consideration of the issue	<p><b>Test question:</b></p> <p>1. To what extent do you have a <b>specific interest in genetic technologies</b> [<i>uses in humans – London</i>] [<i>uses in plants/ microorganisms – Norwich</i>] [<i>uses in animals – Edinburgh</i>] and their uses on a scale of 1-5 where 1= I have no specific interest 5= I have a specific interest* in a specific application?</p> <ul style="list-style-type: none"> <li>• 90% of participants will answer 1, 2 or 3 to the test question</li> <li>• 10% who answer 4/5 to test question 1 are included in the dialogue</li> </ul> <p>*Fieldworker to probe – what interest/ level of interest/ how this interest manifests itself. We are seeking to recruit three ‘actively interested’ participants to each group of 30.</p>
Geographic location	Norwich and Edinburgh should recruit from both urban and rural locations (50/50). London should be an urban recruitment exercise
Experience of market research/ dialogue	Should not have taken part in a focus group / public dialogue in the last six months

Note: please **do not** recruit friendship pairs or use snowballing techniques.

## Appendix 3. Process plan samples for each dialogue round

Locations & Venue	Dates	Focus	Team
<b>Norwich:</b>	R1: Tues 12/09/17 R2: Sat 07/10/17	The uses of genetic technologies in plants and microorganisms, including as sources of food, medicines, or raw materials.	LF: Henrietta Hopkins F: Anita van Mil F: Suzannah Kinsella
<b>London:</b>	R1: Wed 13/09/17 R2: Fri 29/09/17	Near to medium-term future (0 – 10 years from the present) scenarios for the uses of genetic technologies in humans including heritable and non-heritable interventions for both the treatment and prevention of disease and disability, and the enhancement of traits and abilities.	LF: Suzannah Kinsella F: Anita van Mil F: Henrietta Hopkins
<b>Edinburgh:</b>	R1: Thurs 21/09/17 R2: Sat 14/10/17	The uses of genetic technologies in animals, including animals as pests, sources of food, companions and wild creatures.	LF: Anita van Mil F: Suzannah Kinsella F: Henrietta Hopkins

Objectives - (Why we are doing it)	Outcomes - (What we want at the end)
<p><b>Overarching aim to design, deliver and report on a public dialogue to:</b></p> <ul style="list-style-type: none"> <li>• Explore commonalities and differences in attitudes depending on applications, source of the change/ range of material introduced and contexts;</li> <li>• Identify the problems that people feel genetic technologies are well placed to solve as well as the areas in which they would prefer greater emphasis be put on other solutions;</li> <li>• Identify the frames and contexts that moderate the public acceptability of developing UK research into genetic technologies e.g. UK competitive advantage; individual welfare improvement; collective welfare improvement; and environmental improvement;</li> <li>• Identify who is trusted to work on particular technologies or applications, why, and with what implications e.g. public vs. private researchers; for profit vs. not for profit commercial organisations.</li> </ul> <p><b>Round 1 objectives – to:</b></p> <ul style="list-style-type: none"> <li>• Build participant trust in the process</li> <li>• Develop a rapport between facilitators, participants and specialists present</li> </ul>	<p>As a result of the public dialogue the Royal Society will have gained <b>in-depth understanding of the views of the public</b> on the uses of genetic technologies applied to plants, micro-organisms and animals and gathered input to inform early debate around future uses of genetic technologies in humans.</p>

<ul style="list-style-type: none"> <li>• Enable participants to gain essential contextual knowledge of the subject so that all participants can work together effectively whatever their initial understanding</li> <li>• Begin initial discussions on the subject</li> <li>• Lay the foundations for in-depth dialogue in round 2</li> </ul>	
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Time	Agenda	Process for Round 1 London	Who?	Process tools	Expected outcomes
4:00-6.00	Set-up	HVM teams to set up dialogue spaces. 1 reception desk with packs/ badges/ sign-in sheets 1 plenary space + projector and screen plus genetic technologies timeline on the wall. Check AV equipment 3 small group areas with flip stands, banked blank flips and pre-prepared flips for the session.	LF & Fs	Information packs Name badges Process on flips Projector Screen Facilitation kits Recorders AOT cards GT Timeline GT definition Focus for this location up on the wall Audio Visual equipment	Space ready for dialogue
Preparation 5.30-6.00	Arrivals & registration  Briefing for specialists/ observers	Sign-in sheet to be completed & participants sign-posted to refreshments/ loos/ plenary area/ their small group table & given their badge and the printed packs.  Lead Facilitator will brief all non-participants on the process.	F  LF	Sign-in sheet Sticky dots (red/ blue/ green)	All those present ready to start the day.
6.00-6.20 (20 mins)	Welcome & introductions	Housekeeping Welcome slides are displayed and presented which include the dialogue aims and purpose. <ul style="list-style-type: none"> <li>• All non-participants are asked to stand up and introduce themselves and their interest in being part of the public dialogue</li> <li>• Transparency on the process</li> <li>• What's on the table for discussion and what is not</li> </ul>	LF	Welcome slides to talk through  VPs ready to go Sound box	Everyone knows who is in the room and why; what will happen during the day and their role in it.
6.00-6.15 (15 mins)		Vox pops – a filmed introduction to the dialogue from the Royal Society and Contact Group members.			Making participants feel comfortable in the space (physically/ intellectually/ emotionally)
6.15-6.20 (5 mins)		Explanation of small groups.			

<p>6.20-6.50 (30 mins)</p> <p>6.20-6.25 (5 mins)</p> <p>6:25-6:35 (10 mins)</p> <p>6:35-6:45 (10 mins)</p>	<p>Warm-up</p>	<p>Facilitator to <b>tell</b> the group about the <b>recorder</b>: All recording is anonymous and no comments whether written or recorded will be attributed to a named individual in the report. <b>We are interested in what you are saying not who says what.</b> We use recording to back up the notes being made on the flip chart and to help us write a report on what you have all said to us.</p> <p>Ask if anyone objects. In which case the recorder will be turned off when they are speaking.</p> <p>We also have other ways of making sure we've really captured what you have to say. We use <b>post-its</b> to give you time to think something through. These will be collected up by the facilitator. We also have <b>any other thoughts cards</b>. You can write on these at any time, with any comment, thought or question you have on the issue at hand. Leave the comment card upside down in the centre of your table and it will be collected and reviewed with the rest of the report material.</p> <ul style="list-style-type: none"> <li>▪ Introduce yourself to the person next to you</li> <li>▪ Talk in pairs</li> </ul> <p>We asked you to think about what you might already know about genetic technologies. If you brought in a picture/ news story/ notes on what you know, please share them with your neighbour, otherwise just discuss what you are aware of on the subject. Remember our focus here in London is uses of genetic technologies in humans.</p> <p><b>Facilitators' note:</b> This is a brief discussion – reminder to the group that we'll be talking about these things a lot more during the next 2 sessions.</p> <p><b>Recorder on</b></p> <p>A moment for round the table introductions (or do earlier).</p> <p><b>Q:</b> Given what you've just been discussing, what do these things tell you about the big issues facing society today?</p> <p><b>Facilitators' note:</b> you can talk about all sorts of societal challenges here, not just restricted to the focus for your location, but make sure the group comes to points relating to humans by the end of the discussion.</p> <p><b>Prompts</b> to be used as necessary – for example</p>		<p>Recorder AOT cards Pens on table</p> <p>Flip for recording main points</p>	<p>The groups, facilitators, speakers and observers get to know each other. The subject is introduced and headline themes discussed.</p>
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6:45-6:50 (5 mins)		<ul style="list-style-type: none"> <li>▪ Health</li> <li>▪ Poverty</li> <li>▪ An ageing population</li> <li>▪ Feeding a growing population</li> <li>▪ Climate change</li> <li>▪ Sustainability</li> </ul> <p>We now have a list of challenges faced by society.</p> <p><b>Q:</b> Given what you understand about genetic technologies at the moment, how, if at all, do they relate to this list in your view?</p> <p><b>Recorder off</b> – back to plenary room</p>		Record key points on the flip charts	
6:50-7:10	Contextual information on genetic technologies	<p>Introduce the timeline up on the wall</p> <p>Speaker to present a brief PP.</p> <p>Facilitators to hand out Editing Embryos case study. Speaker will briefly share the key points raised on it to inform subsequent discussions.</p> <p>Clarify that we'll be going in to our small groups to devise questions on the presentation.</p> <p>Leads in to showing of <i>What is gene editing and how does it work?</i></p> <p>Back in to small groups</p>	LF  Speaker  Fs  LF	Timeline PP presentation	<p>Participants gain an understanding of the long history of genetic technologies and see the speed of developments has increased since the 1950s.</p> <p>An understanding of cells/ genes and the building blocks needed for the rest of the discussion.</p>
7:10-7:30  7:10-7:20 (10 mins)	Question development	<p>Take a minute to read through the case study. We will be using this to stimulate our thinking for the rest of the session.</p> <p><b>Q:</b> As you think about what you have just heard in the presentation, the case study and the animation what thoughts are on your mind?</p> <p><b>Prompts</b> to be used as necessary – for example</p> <ul style="list-style-type: none"> <li>▪ Are there any specific words/ phrases that need more explanation/ a clearer definition?</li> <li>▪ What points need clarification?</li> <li>▪ What are the issues raised for you in these examples?</li> </ul>	Fs  All	Case study for each participant PP in pack	A chance to interrogate the stimulus materials

7:20-7:30 (10 mins)		<ul style="list-style-type: none"> <li>What else do you need to know to inform your discussions?</li> </ul> <p>Talk to your neighbour Write down specific points on post-its (one thought per post-it)</p> <p>Come back as a group:</p> <p><b>Recorder on</b></p> <p>Discuss the points raised and collate them on the flip chart</p> <p><b>Q:</b> Which are the 3 most important points you wish to raise after the break with the whole group and the specialist observers in the room?</p> <p><b>Q:</b> What are the words/ phrases that need clarifying?</p> <p><b>Recorder off</b></p> <p>Volunteers to ask the questions/ make the statements.</p>		Post-it collating sheet 3 points sheet	
7:30-7:50 (20 mins)	Break	Chance to review the timeline/ add comments/ ask questions informally of the specialist observers	All	Refreshments	A pause + reflection time
7:50-8:10 (30 mins)	Plenary discussion	<p><b>Recorder on</b></p> <p>Go round the room. Each small group asks their point 1. Most appropriate person in the room responds. Continue in this way until each small group has raised 3 points. Make sure that Post-its are used to capture additional points to add to the core definitions included in the jargon buster</p> <p>If time available:</p> <p><b>Q:</b> Are there any further points/ comments that this discussion raises for you?</p> <p><b>Recorder off</b></p> <p>Reminder on AOT cards to close discussion.</p>	LF	<p>Flip to record additional key points</p> <p>Post-its for additional definition of terms</p> <p>AOT cards to collect questions to be answered at the beginning of round 2</p>	Common understanding of what has been presented, key questions answered, outstanding questions captured and agreement reached on how to deal with them.
8:10-8:40 (30 mins)  8:10-8:20 (10 mins)	Hopes and fears	<p>Back in small groups</p> <p><b>Q:</b> Given what has been discussed this evening, and drawing on the case study, what are the <b>hopes</b> and <b>fears</b> you have for using genetic technologies in relation to humans including heritable and non-</p>		Yellow post-its (hopes) Pink post-its (fears)	Front-of-mind hope, fears leading to the R2 discussions

8:20-8:30 (10 mins)		<p>heritable interventions for both the treatment and prevention of disease and disability, and the enhancement of traits and abilities.</p> <p>Work in pairs Use post-its to record all hopes (one yellow post-it per hope) and fears (one pink post-it per fear)</p> <p>Facilitator to run through the groupings for hopes and fears.</p> <p><b>Recorder on</b></p> <p><b>Q:</b> What does this tell us about the opportunities, risks and uncertainties about the use of genetic technologies in relation to humans?</p>		Post-it collating sheet divided into hopes/fears	
8:30-8:40 (10 mins)		<p><b>Prompts</b> to be used as necessary – the balance between Think about what you or others (scientists, regulators) just don't know enough about yet</p> <p>Brainstorming discussion. Leading to agreement on 2 main points the group wishes to make in the plenary discussion.</p> <p><b>Q:</b> What are your reflections on the other solutions that might be used for the global challenge raised by the case study? Are there other solutions that could be considered in your view?</p>		Facilitator to record key points on flip chart in order to present them back to the plenary session which follows.	
		<p><b>Prompts</b> to be used as necessary – the balance between</p> <ul style="list-style-type: none"> <li>▪ Technological</li> <li>▪ Social</li> <li>▪ Political</li> <li>▪ Economic</li> <li>▪ Ethical</li> <li>▪ Regulatory</li> </ul> <p>solutions.</p> <p>Brainstorming discussion. Leading to agreement on 2 main points the group wish to makes in the plenary discussion.</p> <p><b>Recorder off</b></p>		Summary sheet with 4 main points	
8:40-9:05 (25 mins)	Plenary discussion	Final plenary	LF	Summary sheets to plenary area	Round up discussion drawing in further

		Each group presents their summaries (probably facilitator present on this occasion) Discussion with everyone ending in reflections from specialist observers/ Royal Society on what they have heard this evening.	Obs		questions & comment to inform R2
9:05-9:10 (inc flexi)	Pre-round 2 task	LF explanation of task Distribution of interview pro-formas	LF	Pro-formas	Everyone clear on task
9:10-9:15	Evaluation	Ursus to explain evaluation task	E	Incentive receipts Evaluation forms	Understanding of how the session has gone
9.15	Close	<ul style="list-style-type: none"> <li>• Next steps</li> <li>• Call to action – come back for round 2 bringing your findings from your interviews.</li> <li>• Thanks and close</li> <li>• Distribution of initial incentives</li> </ul>		Incentive receipts	People know what will happen next time and the importance of coming back for round 2.

Time	Agenda	Process for Round 2 Edinburgh	Who?	Process tools	Expected outcomes
8:00-10:00	Set-up	HVM teams to set up dialogue spaces. 1 reception desk with packs/ badges/ sign-in sheets 1 plenary space + projector and screen plus genetic technologies timeline on the wall. 3 small group areas with flip stands, banked blank flips and pre-prepared flips for the session.	LF & Fs	Information packs Name badges Process on flips Projector Screen Facilitation kits Recorders AOT cards GT Timeline GT definition Focus for this location up on the wall	Space ready for dialogue
Preparation 9:30-10:00	Arrivals & registration	Sign-in sheet to be completed & participants sign-posted to refreshments/ loos/ plenary area/ their small group table & given their badge and the printed packs.	F	Sign-in sheet Sticky dots (red/ blue/ green)	All those present ready to start the day.
9:30-9:45	Briefing for specialists/ observers	Lead Facilitator will brief all non-participants on the process.	LF		
10:00-10:10 (10 mins)	Welcome & introductions	Housekeeping Welcome slides are displayed and presented which include the dialogue aims and purpose.	LF	Welcome slides to talk through	Everyone knows who is in the room and why; what will happen

		<ul style="list-style-type: none"> <li>All non-participants are asked to stand up and introduce themselves and their interest in being part of the public dialogue</li> <li>Transparency on the process</li> <li>What's on the table for discussion and what is not</li> </ul>			during the day and their role in it.
10:10-10:30	Warm-up	<p>Facilitator to <b>remind</b> the group about the <b>recorder</b>: All recording is anonymous and no comments whether written or recorded will be attributed to a named individual in the report. <b>We are interested in what you are saying not who says what.</b> We use recording to back up the notes being made on the flip chart and to help us write a report on what you have all said to us.</p> <p>Ask if anyone objects. In which case the recorder will be turned off when they are speaking.</p> <p>Reminder that we also have other ways of making sure we've really captured what you have to say. We use <b>post-its</b> to give you time to think something through. These will be collected up by the facilitator. We also have <b>any other thoughts cards</b>. This is a reminder to use them for this session, we find them really useful for our report.</p> <p><b>Recorder on</b> Everyone to very briefly report back on the results of their interviews with family members/ friends. Facilitator to clarify points, probe as necessary</p> <p><b>Recorder off</b></p>		<p>Recorder AOT cards Pens on table</p> <p>Flip for recording main points. Collect the completed interview forms.</p>	<p>The groups, facilitators, speakers and observers have an opportunity to get back into the space (physically/ intellectually/ emotionally)</p> <p>Getting a broader view on the subject to inform the survey.</p>
10:30-10:50	Genetic Technologies today	<p>R2 Vox pops from NGOs/ others who have raised concerns/ favour alternative solutions making it clear there are other views. Supported by the timeline where these are expressed. Explain that this film is being shown in each location and does have a bit of a focus on crops.</p> <p>Contextual presentation and introduction to the case studies. An explanation of the type of research currently being undertaken, current legislative frameworks (and changes to them) and potential steps towards the future.</p>	Speaker		An explanation of the type of research currently being undertaken, current legislative frameworks (and changes to them) and potential steps towards the future
10:50-11:10	Question session	Show case study film relevant to your group: Pig organs – Blue Group Salmon – Red Group Mosquitos – Green Group	Fs	Case study for each participant PP in pack	A chance to interrogate the stimulus materials. An

		<p>Take a minute to read through the case study allocated to your table. We will be using this to stimulate our thinking for the rest of the session.</p> <p><b>Q:</b> As you think about what you have just heard in the presentation, the case study and the vox pops what questions would you like to ask in the next plenary session?</p> <p><b>Prompts</b> to be used as necessary – for example</p> <ul style="list-style-type: none"> <li>Are there any specific words/ phrases that need more explanation?</li> <li>What points need clarification?</li> <li>What else do you need to know to inform your discussions?</li> </ul> <p>Talk to your neighbour Write down specific points on post-its (one thought per post-it)</p> <p>Come back as a group:</p> <p><b>Recorder on</b></p> <p>Discuss the points raised and collate them on the flip chart</p> <p><b>Q:</b> Which are the 2 most important points you wish to raise with the whole group and the specialist observers in the room?</p> <p><b>Recorder off</b></p>	All	<p>Post-it collating sheet</p> <p>2 points sheet</p>	initial understanding of participant views.
11:10-11:40 (30 mins)	Plenary Q&A	<p><b>Recorder on</b></p> <p>Go round the room. Each small group asks their point 1. Most appropriate person in the room responds. Continue in this way until each small group has raised 2 points.</p> <p><b>Recorder off</b></p> <p>Reminder on AOT cards to close discussion.</p>			
11:40-11:55	Break	Participants steered back to timeline to reflect more on quotes/ add other thoughts. Facilitators sign participants for vox pop filming over lunch.		IDENTIFY VOX POP CANDIDATE	

<p>11:55-12:45 (50 mins)</p> <p>11:55-12:00 (5 mins set up)</p>	<p>Put yourself in their shoes</p>	<p>Return to the case study. Imagine you are at a meeting with [Facilitator to hand out cards randomly]:</p> <ul style="list-style-type: none"> <li>▪ Businesses working in genetic technology [examples: GE Healthcare, AquaBounty, Monsanto]</li> </ul> <p><b>Core value:</b> Develop and deliver products or services for a profit</p> <ul style="list-style-type: none"> <li>▪ Government bodies/ policy makers [examples: NHS, Department for Food, Environment &amp; Rural Affairs]</li> </ul> <p><b>Core value:</b> Fulfilling a broad remit to provide services, safeguard, support and sustain through the implementation of government policy in the UK.</p> <ul style="list-style-type: none"> <li>▪ Charities/ Trusts and Foundations (including campaigning organisations) [examples: Green Peace, Human Genetics Alert, Animal Aid or British Heart Foundation, Bill &amp; Melinda Gates Foundation, Royal Society for the Protection of Birds]</li> </ul> <p><b>Core value:</b> Delivering a public benefit/ championing a particular cause</p> <ul style="list-style-type: none"> <li>▪ Privately funded academics/ scientists/ researchers [examples John Innes Centre which secures industry funding alongside government funding]</li> </ul> <p><b>Core value:</b> funded by both private and public funding, using the scientific method to add knowledge and insight to our common understanding, as well as conducting research to ignite new discoveries for the future</p> <ul style="list-style-type: none"> <li>▪ Professional/ specialist networks [example The Royal Society]</li> </ul> <p><b>Core value:</b> Providing advice, support and a platform for our members whilst advising on and engaging society in our areas of expertise</p> <ul style="list-style-type: none"> <li>▪ Regulatory organisations [examples: Food Standards Agency, Human Fertilisation &amp; Embryology Authority, Gene Therapy Advisory Committee, EU Frameworks]</li> </ul> <p><b>Core value:</b> Ensuring work is conducted to the highest professional and ethical standards as well as complying with all relevant UK and global legislation</p> <ul style="list-style-type: none"> <li>▪ University academics/ scientists/ researchers [examples: Francis Crick Institute, Rothamsted Institute University of Edinburgh, Sainsbury Laboratory University of Cambridge]</li> </ul> <p><b>Core value:</b> Using the scientific method to add knowledge and insight to our common understanding, as well as conducting research to ignite new discoveries for the future</p>	<p>Fs</p>	<p>Stakeholder cards Coloured pens Newspapers Questions up on flip chart Post-it notes Post-it collation sheet for Qs 1 and 2</p>	<p>Each group will have explored their case study from a range of perspectives.</p> <p>An opportunity to think about the issues from a different perspective</p> <p>Consider how they feel about the issue and provide advice</p>
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<p>12:00-12:15 (15 mins 1<sup>st</sup> 2 Qs)</p>		<p>Use your common sense/ life experience/ the reflections you have on what we've been discussing today and in the previous session to think about what each of the representatives might do in this situation:</p> <ul style="list-style-type: none"> <li>• Pig organs</li> <li>• Salmon</li> <li>• Mosquitos</li> </ul> <p>I've given you a card. See if for a few moments you can think like someone working for this type of organisation, work with the person who has been given the same card [or if insufficient numbers with someone with a different card so that all organisation sets are covered] for a few minutes, and write your thoughts on a post-it, one post-it per thought. If you were at this meeting thinking about next steps for society:</p> <p><b>Q:</b> What are the ethical/ social/ technological/ environmental/ regulatory or other considerations that must be taken in to account?  <b>Q:</b> What other ways could be used to achieve the same outcomes?</p> <p>Facilitator to collate the comments on the post-it collation sheet.  <b>Group discussion:</b></p> <p>Brief group reflection on the post-it notes</p>			
<p>12:15-12:25 (10 mins – flexi time)</p>		<p>Now step away from this role and become yourself again:  <b>Q:</b> If you were advising the group in your personal capacity on next steps what would you tell them?</p> <p><b>Main repeated prompts throughout:</b></p> <ul style="list-style-type: none"> <li>• Why?</li> <li>• What makes you say that?</li> <li>• Tell me more about your thinking?</li> </ul>			
<p>12:25-12:35 (10 mins)</p>		<p>Facilitator to support the whole group to create a visual representation of the short statement to the press the meeting would make about their deliberations as a press release. Facilitator to encourage the group to use the coloured pens/ newspapers to illustrate their meeting statements, use the headings on the summary sheet if it helps.</p>		<p>Group visual to the press might include:</p> <ol style="list-style-type: none"> <li>1. These are our considerations</li> <li>2. These are some other ways we could achieve the same thing</li> <li>3. This is the advice we would give to the meeting</li> </ol>	
<p>12:35-12:50 (15 mins)</p>					

12:50-13:05	Plenary feedback	Groups to bring their visuals to the main plenary area. They will share their findings and reflect on the results	LF All		Think about the discussion across all 3 case studies
13:05-13:45 (40 mins)	Lunch	Filming of participant vox pops. Up to 8 are likely in this time.			
13:45-14:30 (45 mins)	Acceptability/ Unacceptability	<p>Using a roving ideas storm method each small group will visit a separate area of the dialogue space to consider the following:</p> <ul style="list-style-type: none"> <li>• Cost (<i>if using a genetic technology has a lower cost than current technologies for that purpose, is that an acceptable reason to develop the genetic technology?</i>)</li> <li>• Individual welfare</li> <li>• Collective welfare</li> <li>• Environmental impact</li> </ul> <p>In each space the facilitator will probe genetic technologies in the context of the heading. Each group will build on what the previous group to visit the area has said creating a rich picture of views on the subject. The first session allows 15 minutes, subsequent sessions 10.</p> <p><b>Q:</b> What in your view is acceptable for society in terms of this theme?</p> <p>Why?</p> <p><b>Q:</b> What in your view is unacceptable for society in terms of this theme and our focus on plants?</p> <p>Case study reminders:</p> <ul style="list-style-type: none"> <li>• Pig organs</li> <li>• Salmon</li> <li>• Mosquitos</li> </ul> <p>Why?</p>	LF  All	Flips with headings Blue group to use the blue pen Red group to use the red pen Green group to use the green pen	A reflection on what is acceptable/unacceptable in relation to the focus we are discussing. This will draw participants in to discussing the benefits/ risks/ opportunities and threats of GT in relation to other possible solutions.
14:30-15:30 (60 mins)	Trusted/ less trusted actors	Each group is given a set of illustrated cards with actors in the field written on them as set out for each of the rankings. 1 and 2 use a shortened list, 3 and 4 use the full list. Facilitator to work through all 4 rankings taking the sheets away from the participants as they finish each ranking.		Cards Ranking notation sheets Key points sheet(s)	A discussion on trusted/ not trusted and gaining an understanding of why people feel as they do.
		If less time needed for rankings then move it to			

<p>the 'why' discussion. Assumption that 2<sup>nd</sup> ranking quicker than 1<sup>st</sup>.</p>		<p>First two rankings are done first followed by a group discussion on 'Why'.</p>			
<p>R1 14:30- 14:40 (10 mins)</p>		<p>Facilitator to guide participants through 4 mini rankings: 1) Who would you most trust to work on/ develop uses for genetic technologies?</p> <p>For first 2 rankings only use the four categories that work/ develop uses for genetic technologies:</p> <ul style="list-style-type: none"> <li>▪ Businesses working in genetic technology [examples: GE Healthcare, AquaBounty, Monsanto]</li> </ul> <p><b>Core value:</b> Develop and deliver products or services for a profit</p> <ul style="list-style-type: none"> <li>▪ Charities/ Trusts and Foundations (including campaigning organisations) [examples: Green Peace, Human Genetics Alert, Animal Aid or British Heart Foundation, Bill &amp; Melinda Gates Foundation, Royal Society for the Protection of Birds]</li> </ul> <p><b>Core value:</b> Delivering a public benefit/ championing a particular cause</p> <ul style="list-style-type: none"> <li>▪ Privately funded academics/ scientists/ researchers [examples John Innes Centre which secures industry funding alongside government funding]</li> </ul> <p><b>Core value:</b> funded by both private and public funding, using the scientific method to add knowledge and insight to our common understanding, as well as conducting research to ignite new discoveries for the future</p> <ul style="list-style-type: none"> <li>▪ University academics/ scientists/ researchers [examples: Francis Crick Institute, Rothamsted Institute University of Edinburgh, Sainsbury Laboratory University of Cambridge]</li> </ul> <p><b>Core value:</b> Using the scientific method to add knowledge and insight to our common understanding, as well as conducting research to ignite new discoveries for the future</p>			
<p>R2 14:40-14:45 (5 mins)</p>		<p>Ask participants to put ranking sheet 1 to one side and distribute ranking sheet 2. Explain that they should do both rankings as they might come up with different findings than simply the reverse of 'most trust'.</p>			
<p>R1_R2 why? 14:45-14:55 (10 mins)</p>					

<p>R3 14:55-15:05 (10 mins)</p>		<p>2) Who would you least trust to work on/ develop uses for genetic technologies?</p> <p><b>Discuss as a group:</b></p> <ul style="list-style-type: none"> <li>- What are the rankings for 1 and 2?</li> <li>- Why have you ranked them in this way?</li> </ul> <p>3) Who would you most trust to advise and inform on genetic technologies and their uses?</p> <p>Now use full list:</p> <ul style="list-style-type: none"> <li>▪ Businesses working in genetic technology [examples: GE Healthcare, AquaBounty, Monsanto]</li> </ul> <p><b>Core value:</b> Develop and deliver products or services for a profit</p> <ul style="list-style-type: none"> <li>▪ Government bodies/ policy makers [examples: NHS, Department for Food, Environment &amp; Rural Affairs]</li> </ul> <p><b>Core value:</b> Fulfilling a broad remit to provide services, safeguard, support and sustain through the implementation of government policy in the UK.</p> <ul style="list-style-type: none"> <li>▪ Charities/ Trusts and Foundations (including campaigning organisations) [examples: Green Peace, Human Genetics Alert, Animal Aid or British Heart Foundation, Bill &amp; Melinda Gates Foundation, Royal Society for the Protection of Birds]</li> </ul> <p><b>Core value:</b> Delivering a public benefit/ championing a particular cause</p> <ul style="list-style-type: none"> <li>▪ Privately funded academics/ scientists/ researchers [examples John Innes Centre which secures industry funding alongside government funding]</li> </ul> <p><b>Core value:</b> funded by both private and public funding, using the scientific method to add knowledge and insight to our common understanding, as well as conducting research to ignite new discoveries for the future</p> <ul style="list-style-type: none"> <li>▪ Professional/ specialist networks [example The Royal Society]</li> </ul> <p><b>Core value:</b> Providing advice, support and a platform for our members whilst advising on and engaging society in our areas of expertise</p>		<p>Gather key 'why' points on the flip chart.</p>	
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<p>R4 15:05-15:10 (5 mins)</p> <p>R3_R4 why? 15:10-15:20</p> <p>15:20-15:25 (5 mins)</p> <p>15:25-15:30 (5 mins)</p>		<ul style="list-style-type: none"> <li>Regulatory organisations [examples: Food Standards Agency, Human Fertilisation &amp; Embryology Authority, Gene Therapy Advisory Committee, EU Frameworks]</li> </ul> <p><b>Core value:</b> Ensuring work is conducted to the highest professional and ethical standards as well as complying with all relevant UK and global legislation</p> <ul style="list-style-type: none"> <li>University academics/ scientists/ researchers [examples: Francis Crick Institute, Rothamsted Institute University of Edinburgh, Sainsbury Laboratory University of Cambridge]</li> </ul> <p><b>Core value:</b> Using the scientific method to add knowledge and insight to our common understanding, as well as conducting research to ignite new discoveries for the future</p> <p>Ask participants to put ranking sheet 3 to one side and distribute ranking sheet 4. Explain that they should do both rankings as they might come up with different findings than simply the reverse of 'most trust'.</p> <p>4) Who would you least trust to advise on genetic technologies and their uses?</p> <p><b>Discuss as a group:</b></p> <ul style="list-style-type: none"> <li>- What are the rankings?</li> <li>- Why have you ranked them in this way?</li> <li>- Given our ranking who would we trust to regulate these areas?</li> </ul> <p>What are the two key points you have in your mind having discussed these issues:</p> <p><b>Q:</b> Given all that we've discussed who would we trust to regulate this area?</p> <p>Quick agreement on summary sheet with <b>2 key points</b> from the trust discussion focused the 'why?' points, not the ranking specifically. These are the 2 points that have been most important from our discussions.</p>		<p>Gather key 'why' points on the flip chart.</p> <p>A new formulation for regulation?</p> <p>2 key points summary sheet</p>	
<p>15:30-15:40 (10 mins)</p>	<p>Break</p>				
<p>15:40</p>	<p>Plenary</p>	<p>Final plenary with groups reporting back on their 2 key points summary sheet, reactions to what has been said today from the observers present</p>	<p>LF Obs</p>		<p>Key points made are clear</p>

16:00	Close	<ul style="list-style-type: none"><li>• Next steps including reporting</li><li>• Thanks and close</li><li>• Distribution of final incentives</li><li>• Feedback forms/ evaluation activity</li></ul>	LF RS	Incentive receipts Feedback forms	People know what will happen next – they'll understand the important role they've played.
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## Appendix 4. Sample dialogue programmes and help points

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### Programme - Round 1: Tuesday 12<sup>th</sup> September

#### Open Norwich, 20 Bank Plain, Norwich, NR2 4SF

- 5:45 Arrivals and sign in  
Participants are asked to arrive between 5:45 and 6:00, refreshments will be available.
- 6:00 Welcome, introductions and purpose  
Those present will be introduced and their role described. The purpose of the public dialogue, this workshop and how it will run will be explained. An introductory film will be shown.
- 6:15 Discussion in small groups: genetic technologies  
During this session small groups of participants will get to know each other and their facilitator. Participants will discuss any material on genetic technologies they wish to share.
- 6:45 An introductory presentation *A brief history of genetic technologies* will be made  
A case study giving a specific example related to the dialogue focus will be handed out.
- 7:05 Short animation *What is gene editing and how does it work?*
- 7:10 Discussion in small groups  
Groups will prepare the questions they wish to ask/ comments they wish to make on the presentation, animation and the case study.
- 7:30 Break
- 7:45 Whole group discussion  
Each group will ask the questions they have followed by a discussion with the speakers/ specialists present at the session.
- 8:10 Discussion in small groups: hopes and fears  
In which the group will begin to discuss the hopes and fears they have for genetic technologies given what has been discussed and front of mind thoughts on opportunities and risks.
- 8:40 Final whole group discussion  
A reflection on what has been discussed today and what the next steps are.
- 9:05 Presentation of the pre-round 2 task
- 9:10 Thanks and close with a reminder to return for round 2 on Saturday 7 October.  
Feedback forms are completed and incentives are distributed.

### Programme - Round 2: Saturday 7<sup>th</sup> October 2017

- 9:45 Arrivals and sign in  
Participants are asked to arrive between 9:45 and 10:00, refreshments will be available.
- 10:00 Welcome, introductions and purpose

Those present will be introduced and their role described. The purpose of the public dialogue, this workshop and how it will run will be explained. An introductory film will be shown.

- 10:10 **Discussion in small groups: genetic technologies**  
During this session small groups of participants share the results of their interviews.
- 10:30 **Genetic technologies today**  
Contextual information to inform today's discussion.
- 10:50 **Discussion in small groups**  
Groups will prepare the questions they wish to ask/ comments they wish to make on the presentation and the case study.
- 11:10 **Whole group discussion**  
Each group will ask the questions they have followed by a discussion with the speakers/ specialists present at the session.
- 11:40 **Break**
- 11:55 **Discussion in small groups: put yourself in their shoes**  
In which the group will discuss the case study from various perspectives.
- 12:50 **Final whole group discussion**  
A reflection on what has been discussed.
- 13:05 **Lunch**
- 13:45 **Discussion in small groups: acceptability/ unacceptability**  
A fast paced discussion to think through what might be acceptable and unacceptable to society in terms of genetic technologies
- 14:45 **Discussion in small groups: trusted/ less trusted actors**  
A discussion in which the group thinks about who they trust to work in/ advise on genetic technologies.
- 15:30 **Break**
- 15:40 **Final plenary discussion**
- 16:00 **Close**
- 

## Points to Help the Discussion

Thank you for signing up to take part in two workshops to be held from 6-9.15pm on Tuesday 12<sup>th</sup> September and from 10am to 4pm on Saturday 7<sup>th</sup> October at Open Norwich, 20 Bank Plain, Norwich, NR2 4SF. It is important that you attend *both* sessions.

### 1. Aims of the two workshops

In holding these discussions with you the Royal Society aims to:

- Explore commonalities and differences in attitudes depending on uses of genetic technologies, source of the change introduced and contexts;

- Identify the problems that people feel genetic technologies are well placed to solve as well as the areas in which they would prefer greater emphasis be put on other technological solutions;
- Identify the frames and contexts that moderate the public acceptability of developing UK research into genetic technologies e.g. UK competitive advantage; individual welfare improvement; collective welfare improvement; and environmental improvement;
- Identify who is trusted to work on particular technologies or applications, why, and with what implications e.g. public vs. private researchers; for profit vs. not for profit commercial organisations.

The discussions we have at the workshops will be facilitated by Hopkins Van Mil, independent public engagement specialists. We will explain more about the organisations which have brought you together at the beginning of the first workshop.

## 2. Background information

For the purposes of this workshop we are using the following definition of genetic technologies:

- Anything to do with understanding, making or adapting genetic material.

During the workshops information will be given about genetic technologies and their current and potential uses in society. Norwich is one of the three locations in which the public dialogue will be held. The other two are London and Edinburgh. In each location we will discuss the context of the uses of genetic technologies and then focus on one specific use in each location as follows.

Location	Focus
<b>Norwich</b>	The uses of genetic technologies in plants and microorganisms, including as sources of food, medicines, energy or raw materials.
<b>London</b>	Near to medium-term future (0 – 10 years from the present) scenarios for the uses of genetic technologies in humans including heritable and non-heritable interventions for both the treatment and prevention of disease and disability, and the enhancement of traits and abilities.
<b>Edinburgh</b>	The uses of genetic technologies in animals, including animals as pests, sources of food, companions and wild creatures.

We will therefore be focusing on the genetic technologies in relation to plants and microorganisms in our discussions with you in Norwich.

## 3. Before you come to the workshops

A programme for the day is being emailed to you with this document to give you a flavour of what we will be doing. Before you come we would also like you to think about what you might know already about genetic technologies. You are not required to spend long on this activity, but please look for examples in the news or simply think about examples of using genetic technologies that you have heard about in the past. For this workshop we'd like you to focus on the use of genetic technologies in plants and microorganisms, including as sources of food, medical compounds, energy or raw materials. Please bring any notes, press cuttings or simply memories of these points with you to discuss at the workshop.

## 4. Points to remember during the dialogue workshops

The workshops are intended to be interesting and enjoyable. We do not expect those who attend to have any specialist knowledge of genetic technologies, we will provide you with the information you need at the session to have an informed discussion on this subject. To make a good discussion possible at the workshops please note the following:

### *a) Small group allocation*

You have been randomly allocated to one of three small discussion groups based on getting a broad mix of people on each table.

### *b) Confidentiality*

By the end of each workshop we will have a record of all the views expressed but not who said what. The recorded views will form the basis of a summary findings report which will be shared with participants after the event. Voice recordings will be deleted after the analysis phase.

### *c) Making the conversation easier*

- There are no 'stupid' questions or comments. We are interested in all you have to say and welcome your views. Facilitators will record all the points that inform the discussion.
- It is helpful if people are positive in their comments (even if you disagree with someone) – constructive criticism is often very effective in an open discussion.
- Please allow everyone a fair and equal opportunity to speak and try not to interrupt. The facilitators will note that you are trying to make a comment and give you time as appropriate.
- Don't take part in side conversations as it makes it harder for everyone to hear and take part.
- Please come from breaks on time and help the facilitators ensure that each activity ends promptly.
- Please do not use mobile phones during the discussions as it is distracting for the group.

### *d) Your facilitator*

The facilitator helps your group with the discussion. Please remember that the facilitator is there to keep the session to time and give everyone a chance to make the comments they wish to make. So do turn to anyone on the facilitation team for advice if you need more support to make a comment.

### *e) Speakers*

During the sessions we will be given short presentations by people who work in the field of genetic technologies as scientists, researchers, representatives of 3<sup>rd</sup> sector organisations and/ or policy makers and shapers. Speakers will take part in the discussion to answer questions and clarify the things they have said. They will not join in with the small group discussions, unless asked, but they may drop-in to listen to what is being said.

### *f) Observers*

Other people who work in the field of genetic technologies as scientists, researchers, representatives of 3<sup>rd</sup> sector organisations and/ or policy makers and shapers will be present to observe the process. These will include representatives from the Chinese Academy of Sciences who are interested in how this public dialogue is being run. Observers are not in the room to take part in the discussion so please don't worry if they don't make any comments, they are listening to what takes place to understand participants' views and to see how the workshop is being delivered.

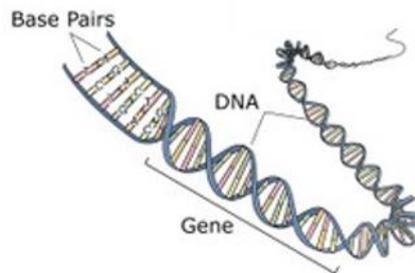
We look forward to seeing you on Tuesday 12 September.

## Appendix 5. Jargon buster

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Here are some words and phrases that might come up in our discussions with a brief explanation of what they mean. This is to help you during the two workshops. We will also have expert advisers present to help with our understanding of the subject. You do not have to learn the words or work on them before taking part.

**Image 1: The structure of DNA** A double helix with base pairing [7]



**Allele** An allele is one of two or more versions of a gene. An individual inherits two alleles for most genes, one from each parent. [1] The exception are sex-linked genes on the X and Y chromosomes in men, where a single X chromosome is inherited from the mother and a single Y chromosome from the father. Women have two X chromosomes (and no Y).

**Bacteria** Bacteria are small single-celled organisms. Bacteria are found almost everywhere on Earth and are vital to the planet's ecosystems. The human body is full of bacteria, and in fact is estimated to contain more bacterial cells than human cells. Most bacteria in the body are harmless, and some are even helpful. A relatively small number of species cause disease. [1]

**Base** The basic unit of our genetic instructions: DNA instructions are encoded in the sequence of its chemical 'letters' or bases. There are four bases: adenine (A), cytosine (C), guanine (G) and thymine (T). Another base, uracil (U) replaces T in RNA. [2]

**Base pair** A base pair is two chemical bases bonded to one another forming a "rung of the DNA ladder." [1] See image 1

**Cell** A cell is the basic building block of living things. [1]

**Chromosome** A chromosome is an organized package of DNA (each comprising a single molecule) found in the nucleus of the cell. Different organisms have different numbers of chromosomes. Humans have 23 pairs of chromosomes. Each parent contributes one chromosome to each pair so that offspring get half of their chromosomes from their mother and half from their father. [1]

**CRISPR-Cas9** CRISPR-Cas9 is a genome editing tool that is creating a buzz in the science world. It is faster, cheaper and more accurate than previous techniques of editing DNA and has a wide range of potential applications. CRISPR is a molecular system that guides a protein called Cas9 towards a chosen sequence of DNA. Cas9 cuts the DNA at that chosen sequence. [2]

**DNA** Deoxyribonucleic acid. A two-stranded molecule (arranged as a double helix) that contains the genetic instructions used in the development, functioning and reproduction of all known living organisms. [3] See image 1

**DNA sequencing** DNA sequencing is a laboratory technique used to determine the exact sequence of bases (A, C, G, and T) in a DNA molecule. [1]

**Dominant** The stronger version of a pair of alleles. Dominant alleles show their effect even if there is only one copy in the genome, for example the allele for brown eyes. [2]

**Double helix** The structure formed by double-stranded molecules of DNA. [2] It has the shape of a twisted ladder.

**Enzyme** Proteins that act as biological catalysts, speeding up or kick-starting chemical reactions. [3]

**Evolution** Adaptation based on the process of natural selection. Successful organisms survive and reproduce while unsuccessful ones die off. [2]

**Gene drive** The process of stimulating the biased inheritance of specific genes. This can be achieved in the lab by having the genome editing components engineered into cells or organisms in such a way that they copy themselves into the other allele. If this occurs in the cells that become eggs or sperm they will be inherited by all offspring and spread throughout the population. [4]

**Gene** The gene is the basic physical unit of inheritance. Genes are passed from parents to offspring and contain the information needed to specify traits. Genes are arranged, one after another, on structures called chromosomes. [1] See image 1

**Gene therapy** The treatment of a disease by introducing modified DNA into the cells of the patient. [2]

**Genetic engineering** Genetic engineering refers to the direct manipulation of DNA to alter a cell or an organism's characteristics in a particular way. It is used by scientists to enhance or modify the characteristics of an individual organism. [2]

**Genetic inheritance** The process by which genes and characteristics are passed down from parent to offspring. [2]

**Genetic material** Genetic material can be a gene, a part of a gene, a group of genes, a DNA molecule, a fragment of DNA, a group of DNA molecules, or the entire genome of an organism.

**Genetic technologies** Anything to do with understanding, making or adapting genetic material.

**Genetic testing** A tool for identifying changes in DNA that could increase the risk of developing a disease. [2]

**Genome editing** The process of making a precise change or changes to the DNA sequence that makes up the genome in a cell by removing, replacing, or adding new parts. [3]

**Genome** The complete set of DNA that makes up an organism. In humans, the genome is organized into 23 pairs of chromosomes. [3]

**Germ cell** A cell at any point in the lineage (or sequence) of cells that will give rise to sperm or eggs. [3]

**Germ line** The germ line is the lineage (or sequence) of cells that will give rise to sperm or eggs. [3]

**GMO** Genetically Modified Organism. An organism that has had its genome changed by direct manipulation of its genes in a way that does not happen normally in nature. [2]

**Molecule** A molecule is the smallest unit of a substance that has all the properties of that substance. For instance, a water molecule is the smallest unit that is still water. A water molecule can be divided into smaller parts called atoms. This produces two hydrogen atoms and one oxygen atom. But these atoms alone do not have the properties of water. [5]

**Mutation** A change that occurs in a DNA sequence. Mutations are relatively common in our DNA, but most have no detectable effect. [2]

**Natural selection** The process where those organisms better adapted to their environment survive and pass on their beneficial characteristics to their offspring. [2]

**Nucleotide** A nucleotide is the basic building block of nucleic acids. RNA and DNA are polymers made of long chains of nucleotides. [1]

**Off-target events (sometimes called off-target effects)** An edit or change to the genetic sequence that occurs at a different place in the genome from where it was supposed to. May or may not cause a noticeable effect. [3]

**Organism** Any living biological entity, such as an animal, plant, fungus, or bacterium. [6]

**Proteins** Proteins are an important class of molecules found in all living cells. A protein is composed of one or more long chains of amino acids, the sequence of which corresponds to the DNA sequence of the gene that encodes it. [1]

**Recessive** When the allele of a gene shows its effect only if both copies in the genome are the same, for example the allele for blue eyes. [2]

**Recombinant DNA** Recombinant DNA (rDNA) is a technology that uses enzymes to cut and paste together DNA sequences of interest. The recombined DNA sequences can be placed into vehicles called vectors that ferry the DNA into a suitable host cell where it can be copied or expressed. [1]

**RNA** Ribonucleic acid. A single strand of genetic code important in many different biological functions including the decoding and regulation of genes. [3]

**Selective breeding** The process of breeding animals or plants to bring out particular desirable characteristics in future generations. [2]

**Somatic cell** Any cell in the body that does not give rise to eggs or sperm – i.e. all cells in the body that are not part of the germline. [3]

**TALENs** Transcription-Activator Like Effector Nucleases. A method of genome editing, this system followed ZFNs and preceded CRISPR-Cas9. It is largely being replaced by the latter, but it is still being used for genome editing, both clinically in humans for somatic gene therapies and in animals for germline alterations. It can be very precise, but it tends to be less efficient (and more costly) than CRISPR-Cas9. [3]

**Trait** A trait is a specific characteristic of an organism. Traits can be determined by genes or the environment, or more commonly by interactions between them. [1]

**Transgene** A gene or genetic material that has been transferred from one organism to another. (The latter is referred to as being transgenic.) [3]

**ZFNs** Zinc-Finger Nucleases. One of the first and a reliable method of genome editing. Less efficient and much more expensive and cumbersome to use than CRISPR-Cas9, but ZFNs are being employed for several somatic gene therapies and in research. [3]

## References

[1] National Human Genome Research Institute Talking Glossary

[2] yourgenome.org Glossary

[3] Wellcome Trust Glossary of Terms Relevant to Genome Editing

[4] Champer, Jackson, Anna Buchman, and Omar S. Akbari. "Cheating evolution: engineering gene drives to manipulate the fate of wild populations." *Nature reviews. Genetics* 17.3 (2016): 146.

[5] Britannica Student Encyclopedia

[6] Collins Online Dictionary

[7] <http://www2.le.ac.uk/projects/vgec/highereducation/topics/dna-genes-chromosomes>

# Appendix 6. Genetic technologies timeline

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## 1. Influencing evolution

### Domesticating and selecting dogs<sup>1</sup>

There is evidence that humans began domesticating dogs, which evolved from wolves, perhaps 30 to 40 thousand years ago. Although there is some controversy as to where this began, reviewing the essential elements of their genetic material has suggested that dogs originating in China were perhaps the first to be domesticated. Perhaps unconsciously at first, humans began to work with dogs to help with scavenging and hunting.<sup>2</sup> They may then have identified those that were tame (or could be tamed) and invited them to share their food and living environments, to which the dogs then adapted. There is evidence of people in Siberia using different, artificially selected breeds of dog to either hunt or to pull sleds from nine thousand years ago<sup>3</sup>. Selective breeding for different traits (size, speed, coat colour and type, etc) in the subsequent nine thousand years has led to the many different breeds of dog in the world today.

*"I think there were a lot of different kinds of dogs—and maybe even some wolves—mating with each other, producing random litters of pups. From those litters, however, humans may have selected the best sled dogs, which would still indicate some sort of focus on breed. It fills in a missing piece of the puzzle of early human-dog relationships, and even domestication itself."* Angela Perri, a zooarchaeologist at the Max Planck Institute for Evolutionary Anthropology in Leipzig, Germany, May 2017

### Domesticating and selecting plants<sup>4</sup>

Around 10 thousand years ago, humans began to domesticate plants such as wheat, barley, lentils and peas for farming purposes. If we look at current forms of Brassica oleracea (the scientific name for plants in the cabbage family which originated in southern and western Europe), we can see it has been variously selected for its leaves (to become cabbage and kale), its stems (to become kohlrabi), its flower shoots (to become broccoli and cauliflower) and its buds (to become Brussels sprouts).<sup>5</sup>

## 2. Understanding evolution and genetics

### Understanding natural selection

1859: After the famous second voyage of HMS Beagle, Charles Darwin wrote *On the Origin of Species*, which is the basis of our modern understanding of evolution. *On the Origin of Species* led to much speculation on the (as yet undiscovered) genetic mechanisms that give rise to individual differences that can be inherited on which natural selection, and therefore evolution, operates. Darwin was the first person to use the term 'selective breeding'.

*"Occasionally ideas change history. Charles Darwin's theory of evolution by natural selection falls into this category, making Darwin one of the most important thinkers of modern times. He helped to transform how people thought about the natural world and humans' place within it."* Carolyn Burdett, Senior Lecturer in English Literature and Victorian Studies at Birkbeck, University of London, May 2017

### Discovery of the nature of heritability

1865: Gregor Mendel, an Austrian monk, carried out extensive experiments on peas, 'crossing' them, by transferring pollen from the male part of one pea plant to the female part of another, using a paintbrush. By observing and recording the outcomes of his experiments, Mendel found out how likely it is that traits such as colour and stem length are passed on from one generation to the next. In effect, his work laid the foundations for our modern understanding of genetics.

### Ionising radiation and chemicals were found to induce heritable mutations

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<sup>1</sup> <https://www.nature.com/articles/ncomms2814>

<sup>2</sup> Driscoll, Carlos A., David W. Macdonald, and Stephen J. O'Brien. "From wild animals to domestic pets, an evolutionary view of domestication." *Proceedings of the National Academy of Sciences* 106. (2009): 9971-9978

<sup>3</sup> <http://www.sciencemag.org/news/2017/05/earliest-evidence-dog-breeding-found-remote-siberian-island>

<sup>4</sup> <http://science.sciencemag.org/content/341/6141/65>

<sup>5</sup> Sauer, J D 1993 *Historical geography of crop plants – a select roster*. CRC Press: Boca Raton.

1927: Hermann Muller generated mutations in fruit flies by means of X-ray irradiation. 1936: Lewis Stadler generated mutations using UV radiation on maize. 1947: Charlotte Auerbach and John Robson generated mutations in fruit flies using mustard gas.

### **The importance of DNA for inheriting characteristics**

1943: Avery, McLeod and McCarty provided the first clear suggestion that DNA carries genetic information and not protein in experiments on bacteria.

1952: Hershey and Chase proved that it is the DNA in phage (a type of virus that infects bacteria) that carries genetic information.

### **Discovery of the structure of DNA**

1953: Jim Watson and Francis Crick used data collected by Rosalind Franklin and Raymond Gosling to discover the structure of DNA. This was a key moment in the lead up to genetic engineering because in order to edit genetic material, its structure had to be known. Their work explains how genetic information is replicated and passed on to future generations. The four letters in the DNA alphabet, A, C, G, T, are arranged in a specific order to make up genes (both the parts of a gene that encode for proteins, and parts that control when and where the genes are active, or expressed).

*"Francis Crick made not one but many great scientific discoveries. He found that genes are digital codes written on DNA molecules, he found that the code is written in three-letter words and he was instrumental in cracking the code. Any one of those things would have got him into the scientific pantheon. Discovering all three places him alongside Newton, Darwin and Einstein."* Dr Matt Ridley, author of *Genome and Nature Via Nurture*, July 2004

*"The discovery of the structure [of DNA] was of great interest to biologists because it immediately suggested a mechanism whereby DNA could replicate faithfully - one of the great unknown questions of the time. Each DNA strand can act as a template for a separate double helix, so when a cell divides, its DNA physically divides and becomes a template for a new complete DNA molecule."* Science Museum website, accessed September 2017

## **3. Genetic engineering**

*"Once we begin to consciously design ourselves, we will have entered a completely new era of human history, in which human subjects, rather than being accepted as they are will become just another kind of object, shaped according to parental whims and market forces."* Dr David King, founder of Human Genetics Alert

### **The Biological and Toxin Weapons convention**

1972: This is a UN convention that has been signed and ratified by the UK. It includes the provision that "Each State...undertakes never in any circumstances to develop, produce, stockpile or otherwise acquire or retain microbial or other biological agents...of types and in quantities that have no justification for prophylactic, protective or other peaceful purposes." Under the Convention, signatories cannot, for example, produce DNA sequences that might be harmful, or use genetic technologies to create biological weapons.

### **First genetically engineered organism**

1973: Considered 'the birth of biotechnology', Herbert Boyer and Stanley Cohen developed a method of removing genes from the DNA of one organism and putting them into the DNA of another.<sup>6</sup> Their method used an enzyme (complex proteins that join molecules together or split them apart in the body) called EcoRI to cut DNA into fragments, which was then inserted into the recipient DNA (itself also cut with EcoRI), using another enzyme called a ligase. They used it to give antibiotic resistance to a strain of bacteria that did not already have it, making the world's first genetically engineered organism.

### **First genetically engineered animal**

1974: Rudolf Jaenisch and Beatrice Mintz created the first genetically engineered animal. They injected a virus that is found in both monkeys and humans (SV40) into mouse embryos and found that, after birth, the virus was present within the DNA of many of the cells of each mouse. This suggested that the virus had been incorporated into the genome, so a genetically engineered mouse had been deliberately created.

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<sup>6</sup> <https://www.nature.com/naturejobs/science/articles/10.1038/nj6921-456a>

### **Faster DNA sequencing**

1977: Frederick Sanger developed a new method of DNA sequencing (working out the precise order of DNA base pairs) and sequenced a whole genome for the first time: that of a virus called  $\Phi$ -X174 that infects bacteria. Sequencing DNA in the 1980s cost around \$ 6,400 per base pair; it now costs between \$ 0.03 and \$ 0.10 per base pair.<sup>7</sup> The cost of synthesising (making) DNA – a newer technique – is also dropping steadily.

### **Development of in vitro fertilisation (IVF) in humans**

1978: Birth of Louise Brown, the first IVF baby, after work by Patrick Steptoe and Robert Edwards. While initially welcomed by many, there was then a backlash as people feared it would lead to designer babies and genetic modification. IVF is now widely accepted, although not by all, and it has allowed many millions of couples to have children.

### **First “transgenic” animals**

1980: Jon Gordon and Frank Ruddle published the first paper describing direct injection of DNA into the nucleus of fertilised mouse eggs and the birth of several mice that had incorporated the foreign DNA (the “transgene”) into all their cells. The method was developed further by several groups over the following few years, and used to study normal and cancer causing genes, alter growth and physiology, and even produce valuable proteins in not just mice, but in many mammals including sheep, goats and cows. However, it is not a very efficient method, and the genetic material introduced integrates at random in the genome, where it can disrupt the genes already present, sometime with harmful consequences.

### **First genetically engineered pharmaceutical<sup>8</sup>**

1982: After four years of US government deliberation, a company called Genentech – the world’s first biotechnology company received approval to sell its genetically engineered pharmaceutical Humulin for human use as a medication for diabetes. It was made using the technique Herbert Boyer had developed ten years earlier with Stanley Cohen (to cut apart and rejoin DNA fragments) and is still being sold today. Humulin is made by synthesising DNA to mimic the human genes that produce insulin and putting these genes into bacteria. The bacteria then produce insulin, now called Humulin, using that genetic material. This was safer than using insulin extracted from pigs which some patients developed an immune system response to, preventing the insulin from working.

### **UK Animals (Scientific Procedures) Act 1986**

**1986:** The UK Animals Act details the criteria that must be met in order for scientists to modify genes in protected animals (all living animals with a backbone and all cephalopods such as octopus and squid). The main criterion is that modification must not cause an animal ‘pain, suffering, distress or lasting harm.’

### **First precise genetic alterations made by “gene targeting” in mice**

1989: Oliver Smithies, Mario Capecchi, and Martin Evans shared the 2007 Nobel Prize in Medicine for their work developing ‘knock out’ mice – mice in which specific genes have been disabled. This has been a very valuable technique that is still used today to study many aspects of gene function and their roles in embryonic development, physiology, behaviour, cancer, etc. But although a very precise way to alter genes and genomes, it is very inefficient, occasionally goes wrong, and can only be used in the few species for which ES cells can be derived.

### **Environmental Protection Act 1990**

**1990:** The Environmental Protection Act defines genetically modified organisms (GMOs) in UK law for the first time, based on the following definitions:

‘Organism’ defined as “...any acellular, unicellular or multicellular entity (in any form), other than humans, human embryos or human admixed embryos”.

‘Genetically modified’ defined as “...any of the genes or other genetic material in the organism – (a) have been artificially modified or (b) are inherited or otherwise derived...from genes...which were so modified...”

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<sup>7</sup> The Royal Society 2015 Sackler Forum 2015, London: The Royal Society

<sup>8</sup> <http://www.nytimes.com/1982/10/30/us/a-new-insulin-given-approval-for-use-in-us.html>

...genes...in an organism are 'artificially modified' ...if they are altered otherwise than by a process which occurs naturally in mating or natural recombination”.

It contains provision to protect the environment from damage that could be done by the escape or release of GMOs from human control.

### Human Fertilisation and Embryology Act 1990

**1990:** The Human Fertilisation and Embryology Act sets out the rules and guidelines for any research – including genome editing research – involving human embryos and germ cells (cells that produce sperm or eggs). It says that research on human embryos should not be carried out more than two weeks after fertilisation and prohibits the transfer of genetically modified embryos to a woman for gestation. It set up the Human Fertilisation and Embryology Authority to oversee these regulations.

### First genetically modified crop for human consumption<sup>9</sup>

1994: The first genetically modified crop was approved for sale in the US: the Flavr Savr tomato. The Flavr Savr had a longer shelf life than normal tomatoes, staying fresh for up to 30 days, because it had been genetically engineered so as not to produce an enzyme that caused it to soften with age. Production was ceased in 1997 because the company behind the Flavr Savr tomato, Calgene, was unable to produce them profitably.

### First herbicide resistant crop<sup>10</sup>

1996: The US agribusiness Monsanto began selling seeds of its first herbicide resistant crop, the Roundup Ready soybean. These seeds are altered to produce plants that are resistant to a key ingredient of many herbicides: glyphosate and are still sold today. Herbicide resistant crops were developed to enable spraying of herbicides onto established crops to kill weeds without also killing the crops.

*“GM herbicide tolerant crops allow farmers to apply ‘broad spectrum’ weedkillers to their field, which kill all other plants. There is concern that this will continue the decline of farmland wildlife because the use of these GM crops could lead to the removal of weeds from all crops in the normal arable rotation. This will reduce the food supply for insects and birds.”* Friends of the Earth statement on genetically modified crops and food, January 2003

*“GM is a huge distraction. It is diverting a massive amount of time, effort and attention from the really crucial issues facing food and farming - like looking after our soils. We have already degraded 25 to 40% of soils worldwide and unless we work very hard to reverse this damage, it will be impossible to feed the growing population healthily. GM is dangerous because it allows us to accelerate in the wrong direction for a short while longer.”* Helen Browning Soil Association Chief Executive, June 2017

*“There is no evidence that producing a new crop variety using GM techniques is more likely to have unforeseen effects than producing one using conventional cross breeding.”* Royal Society, GM Plants Questions and Answers, May 2016

### First clone produced from an adult animal

1997: Dolly the sheep is the first animal to be cloned by taking the nucleus from an adult cell (in this case from a mammary gland cell line), transferring this into an egg from which the nucleus had been removed, and implanting this egg in a surrogate mother. Subsequently, this has proven to be a successful method to obtain genetically altered animals, such as sheep, pigs, and cows. In these cases, precise changes are made, e.g. by gene targeting, in the genome of the adult cells in culture, before these are used in the cloning procedure. However, the techniques are inefficient and definitely unsafe, because the reprogramming required to go from an adult cell to one capable of embryonic development is often incomplete. These methods could not be applied to humans.

### Arpad Pusztai raises questions over the safety of GM food

<sup>9</sup> <http://www.nytimes.com/1994/05/19/us/fda-approves-altered-tomato-that-will-remain-fresh-longer.html>

<sup>10</sup> <http://www.nytimes.com/1996/11/07/business/genetic-soybeans-alarm-europeans.html>

1998: Arpad Pusztai, a scientist working at the Rowett Institute in Scotland, conducted an experiment feeding GM potatoes to rats and comparing their development with rats fed on non-GM potatoes (the control group). He found that the rats fed on GM potatoes grew slower and had reduced immune system functioning compared with the control group. There has been disagreement ever since as to whether these findings provide evidence that the GM potatoes were unsafe or whether the outcomes were the result of another aspect of the way the experiment was conducted. A series of reviews of Pusztai's data and methodology by scientists not involved in the original experiment have found that the data do not conclusively prove that the abnormalities were caused by the process of genetically modifying the potatoes.

### **Cartagena Protocol on Biosafety to the Convention on Biological Diversity**

**2000:** The Cartagena Protocol regulates the spread, handling and transfer of GMOs across national borders and includes regulations designed to minimise possible negative impacts of genetic technologies on biodiversity. It forms part of the UN Convention on Biological Diversity, which the UK signed and ratified in 1992, and allows countries to ban imports of GMOs if thought unsafe.

### **The Genetically Modified Organisms (Deliberate Release) Regulations 2002**

**2002:** These regulation set out the procedure for scrutinising and approving applications for the release of GMOs from controlled settings to uncontrolled settings. They are an implementation of EU Directive (EC) No 18/2001. They contain provision that people wanting to release a GMO to the environment must apply to the Secretary of State for the Department for Environment, Food and Rural Affairs (DEFRA) and, at the same time, publish a description of the GMO to be released, and the location, purpose and timing of that release, in a national newspaper. They must send notices to local authorities, owners of the site of intended release, members of the genetic medication safety committee, the Association of National Park Authorities, Natural England and the Environment Agency. An assessment of the safety of each application – on a case-by-case basis – is made by an independent group of experts before a release can be approved.

### **First use of zinc-finger nucleases (ZFNs) to edit a genome<sup>11</sup>**

**2002:** Scientists at the University of Utah pioneered a new technique of genome editing that used ZFNs. They used their technique to cut out target sections of DNA from fruit flies, which resulted in mutations and deletions. Compared with previous genetic engineering techniques that involved inserting genetic material at random into an organism's genome, ZFNs enabled precise changes to be made at targeted locations of the genome.

### **First time the human genome is sequenced<sup>12</sup>**

**2003:** The Human Genome Project, begun in 1990, was completed, having sequenced 99% of the 3.2 billion letters (A, C, G, T) that in a specific order carry the instructions to make us distinct from other species as well as from each other. This took 13 years and cost \$3 billion.

### **Regulation 1829/2003/EC**

**2004:** Regulation 1829/2003/EC came into force. It describes the current procedure for evaluating and authorising GM foods and is implemented in the UK by the Genetically Modified Food Regulations 2004. According to these regulations, before GM food can be sold for human or animal consumption, it must first be assessed by the European Food Safety Authority (EFSA). The EFSA might consult with the UK's Food Standards Agency as part of this process. Safety assessments look at the potential for toxic, nutritional or allergenic effects, and any GM food approved for sale in Europe must be labelled as such so that consumers can make an informed decision about whether they want to buy and eat GM foods.

### **The Human Tissue Act 2004**

**2004:** The Human Tissue Act regulates all research and clinical practices in the UK that involve human bodies, organs. One of its main requirements is that consent is given prior to the removal, storage and use

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<sup>11</sup> Bibikova, Marina, et al. "Targeted chromosomal cleavage and mutagenesis in Drosophila using zinc-finger nucleases." *Genetics* 161.3 (2002): 1169-1175

<sup>12</sup> <https://www.genome.gov/10001772/all-about-the--human-genome-project-hgp/>

of human tissues. In terms of genetic technologies it regulates, for example, the genome editing of somatic cells for gene therapy treatments (eg for HIV and cancers).

### **The Human Tissue (Quality and Safety for Human Application) Regulations 2007**

**2007:** These regulations set the standards that must be met by any tissues or cells – including those that have been genome edited – that will be used to treat patients. They are an implementation of the EU Tissues and Cells Directive 23/2004/EC.

### **First use of genetic engineering to target carriers (vectors) of disease**

2010: A British company, Oxitec, ran its first big field trial in Brazil that aimed to use genetic engineering to help limit the spread of the dengue fever disease. They released male mosquitoes (only female mosquitoes bite) that had been genetically engineered to carry a fatal gene. This gene was passed on to the next generation when the released males mated with wild female mosquitoes before dying. The offspring of these matings die before they have a chance to reproduce. Oxitec have since carried out further trials in Panama and the Cayman Islands which they claim have led to a more than 90% reduction in wild mosquito populations. Alternative methods for controlling mosquito populations during dengue fever outbreaks include pesticide spraying programmes and trying to prevent the pools of standing water in which mosquitoes hatch their eggs.

### **The Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising From Their Utilisation to the Convention of Biological Diversity 2011**

**2011:** The Nagoya Protocol obliges signatories to make sure genetic resources benefit both their providers and their users. For example, some plants have genetic properties that make them useful in medicines and can only be found in certain places. Under the Nagoya Protocol, some of the benefit to companies making medicines from these plants must be shared with the people of the place from which the plants came.

### **First use of TALENs to edit a human genome<sup>13</sup>**

2011: Following initial discoveries by Michelle Christian et al in 2010<sup>14</sup>, Scientists and Sangamo Biosciences, Inc. used transcription activator-like effector nucleases (TALENs) to make small deletions and edits within human genes. Using TALENs, they also found that they could change how much a gene was expressed ie the amount of a gene product (such as protein or RNA) that a gene makes. Compared with ZFNs, TALENs are slightly easier to use and make.

### **First use of CRISPR-Cas9 to edit a mammalian genome<sup>15</sup>**

2013: For the first time, the CRISPR-Cas9 system was used by researchers on both human and mouse cells, as a method of genome editing. CRISPR is a molecular system based on RNA that guides a protein called Cas9 to a specific target sequence of DNA. Cas9 then cuts the DNA at that site. DNA repair mechanisms then try to repair the cut DNA, but may leave a small gap or deletion, or even a small insertion. This is an efficient way to make a change in a gene. Alternatively, if new DNA (a DNA template) is introduced at the same time, it can replace the DNA sequence that was previously there. This can be used to alter a single letter (base pair) in the DNA, or many, replace or insert a whole gene, or make precise deletions. Compared with ZFNs and TALENs, CRISPR-Cas9 is easier to use, cheaper to make and more efficient in that edits can be carried out at multiple locations of the genome at the same time, so its development has made genome editing much more accessible. The way CRISPR-Cas 9 is targeted to interact with DNA is also more precise than ZFNs and TALENs.

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<sup>13</sup> Miller, Jeffrey C., et al. "A TALE nuclease architecture for efficient genome editing." *Nature biotechnology* 29.2 (2011): 143-148.

<sup>14</sup> <https://www.ncbi.nlm.nih.gov/pubmed/20660643>

<sup>15</sup> Cong, Le, et al. "Multiplex genome engineering using CRISPR/Cas systems." *Science* 339.6121 (2013): 819-823

Wang H, et al. One-step generation of mice carrying mutations in multiple genes by CRISPR/Cas-mediated genome engineering. *Cell*. 153 (2013): 910-8. (PMID: 23643243)

Jinek M, et al. RNA-programmed genome editing in human cells. *Elife*. (2013) 29;2:e00471. (PMID: 23386978)

Cho SW, et al. Targeted genome engineering in human cells with the Cas9 RNA-guided endonuclease. *Nat Biotechnol*. 31 (2013): 230-2. (PMID: 23360966)

## The Genetically Modified Organisms (Contained Use) Regulations 2014

**2014:** These regulate the genetic modification of organisms in controlled settings, to ensure protection for humans and the environment. They are an implementation of the EU's Contained Use of Genetically Modified Microorganisms Directive 41/2009/EC and draw on the Control of Substances Hazardous to Health Regulations 2002 (COSHH). Scientists, for example, must comply with the Genetically Modified Organisms (Contained Use) Regulations 2014 in order to be allowed to genetically modify plant or animal materials in the laboratory for research purposes.

### First life saved by genome editing<sup>16</sup>

2015: Layla, a patient at Great Ormond Street Hospital was cured of acute lymphoblastic leukaemia. This was made possible by being able to genetically edit donor T-Cells (a type of immune cell) using TALENs. These cells had new genes added to them so that when administered to Layla they became effectively invisible to a powerful leukaemia drug that would usually have killed them. They were also reprogrammed in such a way that they only targeted and fought leukaemia cells.

*"We have only used this treatment on one very strong little girl, and we have to be cautious about claiming that this will be a suitable treatment option for all children. But, this is a landmark in the use of new gene engineering technology and the effects for this child have been staggering. If replicated, it could represent a huge step forward in treating leukaemia and other cancers."* Professor Waseem Qasim, Professor of Cell and Gene Therapy at University College London Great Ormond Street Institute of Child Health, November 2015

*"New technologies such as gene and cell therapies hold out the potential to transform medicine and create an inflection point in our ability to treat and even cure many intractable illnesses"* Food and Drug Administration Commissioner Scott Gottlieb, August 2017

### Genome editing of human embryos<sup>17</sup>

2017: Following on from some earlier attempts by Chinese scientists, which had met with limited success, the CRISPR-Cas9 system was recently used to remove a genetic predisposition to heart disease in human embryos. Although there are still some remaining questions as to whether the editing worked in the way that the authors claimed, it appeared to be efficient and without the undesirable side effects of introducing unintended changes at other places in the genome (off-target effects) or failing to introduce the change equally in all cells (mosaicism). Many of these side effects had been found in the earlier work from China in 2015, 2016 and 2017. The embryos were only allowed to develop for long enough to measure the changes introduced and they were not implanted into women. The USA, where much of the work was carried out, does not allow the implantation and gestation of a gene edited embryo. It is possible that this technology could be used to enable people with hereditary diseases to avoid passing them on to their children and future generations.

### First genetically engineered animal for human consumption<sup>18</sup>

2017: AquaBounty Technologies' genetically engineered salmon went on sale to customers in Canada. This was the first sale made, on the open market, of a genetically engineered animal for human consumption. It should be noted, however, that it took 25 years to gain regulatory approval and get the fish to market. The AquaBounty salmon grows much faster than normal salmon, meaning it is big enough to sell within a shorter timeframe and production costs can be reduced.

*"Do we need a technology that undermines the integrity of nature? We haven't had that debate."* Sue Mayer, director of science for Greenpeace UK, March 2013

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<sup>16</sup> <https://www.newscientist.com/article/dn28454-gene-editing-saves-life-of-girl-dying-from-leukaemia-in-world-first/>

<sup>17</sup> Ma, Hong, et al. "Correction of a pathogenic gene mutation in human embryos." *Nature* 548.7668 (2017): 413-419.

<sup>18</sup> <https://www.newscientist.com/article/2143151-genetically-engineered-salmon-goes-on-sale-for-the-first-time/>

*“The company (AquaBounty) did not disclose where the GM salmon fillets were sold or for what purpose, and we’re shocked to discover that they’ve entered the market at this time,”* Lucy Sharratt of Canadian Biotechnology Action Network, August 2017.

*“The sale and discussions with potential buyers clearly demonstrate that customers want our fish, and we look forward to increasing our production capacity to meet demand,”* Ronald Stotish, CEO, AquaBounty, August 2017

### **Questions raised about whether CRISPR leads to unintended changes in the genome**

2017: Editing genomes using CRISPR leads to changes in the genome at places other than the target gene, referred to as off-target effects. In 2017 researchers published a paper suggesting that CRISPR causes many more off-target effects than had previously been identified, making it a riskier technology, especially if it were ever to be used in people. However the methods used by the researchers have been questioned as has the fact that the results were based on observations in only three mice. Whilst scientists have questioned this particular study, they have also said it highlights the need for further research into potential negative effects of using CRISPR.

### **The future**

#### **First synthetic complex organism<sup>19</sup>**

2017: It is predicted that this year will be the first in which the genome for a complex organism is created from scratch in the lab. The Synthetic Yeast Genome Project is currently in the process of building a yeast genome by shuffling around genes within artificial chromosomes. Whilst yeast might not sound very complex, it has the same specialised structures (organelles), and a nucleus to contain its DNA as human cells and all other plants, animals and fungi. Previously, such work had only been carried out using simpler organisms like bacteria. The work therefore gives insight into the workings of yet more complex organisms.

*“We’re all really excited about seeing the end in sight, but the end is really just the beginning. Once we combine everything into one cell, that’s when the real fun begins. That’s when the power of a fully synthetic genome will become apparent.”* Jef Boeke, New York University Langone geneticist, March 2017

*“Do we wish to be operating in a world where people are capable of organizing themselves to make human genomes? Should we pause and reflect on that question before we launch into doing it? They’re talking about making real the capacity to make the thing that defines humanity — the human genome.”* Drew Endy, Associate professor of bioengineering at Stanford University, June 2016

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<sup>19</sup> <http://syntheticyeast.org/>

## Appendix 7. Case studies

### Case study: Testing for genetic disorders

**Purpose:** A genetic disorder is a disorder that is caused by an abnormality (or several abnormalities) in a person's genome. Genetic disorders are often hereditary, which means they are passed down to a child from its parents. The most common genetic disorder is familial hypercholesterolaemia (a genetic predisposition to high cholesterol levels), which is thought to affect 1 in 250 people in the UK. Other disorders, such as cystic fibrosis, are rarer although they can be relatively common in particular ethnic groups; for instance, the incidence of cystic fibrosis in Scotland is almost double the global average. Collectively genetic disorders affect lots of people because there are more than 10,000 different types worldwide. Genetic testing is used to inform people whether they have a disorder, or if there is a chance they might pass a disorder on to their children.



Photo credit: jxfzsy/ iStockphoto



Photo credit: monkeybusiness/ iStockphoto

#### Approaches to identifying genetic disorders

In the UK, if a person is concerned they might have, or might develop, a genetic disorder based on their family history, they can:

- Go to their GP, who might refer them for genetic testing. Patients usually provide a DNA sample, which is then analysed for a specific abnormality. Usually a single gene will be tested, but whole-genome sequencing approaches are being developed. The 100,000 Genomes Project, for example, aims to study whole-genome sequences from patients with cancer and rare disease
- Use a commercial genetic testing service. In this case, customers collect samples of their own DNA and send them away for analysis and interpretation
- Take no action. Some people decide it is better not to know if they have or might develop a genetic disorder.

#### UK facts & figures

- More than half a million people in the UK have some kind of genetic disorder
- Home genetic testing kits went on sale in the UK in 2014, with some now costing less than £100
- As of 7 August 2017, the 100,000 Genomes Project had sequenced 33,000 genomes
- The current cost of sequencing a whole genome is around £750. This does not include the cost of interpreting the results and employing a genetic counsellor to help people understand the results.

### **Arguments in favour of testing for genetic disorders**

- Identifying a genetic disorder, or predisposition to a genetic disorder, could lead to appropriate treatment, preventative treatment, or behaviours that reduce the risk of disease
- Effective preventative treatment could lead to reduced costs to health services
- Even where no treatment or risk reduction is available, accessing information about their future health can help people make plans for their lives and influence people's reproductive choices such as whether and when to have children, or whether they should use pre-implantation genetic diagnosis
- Having more data about people's genomes improves research into the links between genes and disease.

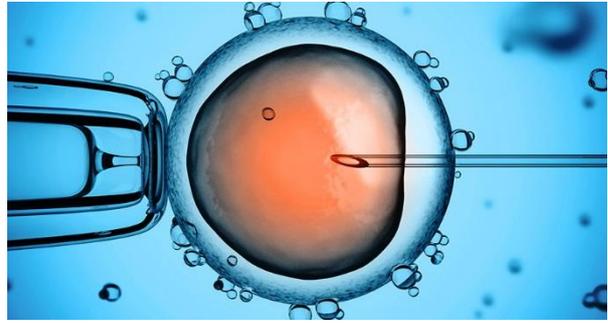
### **Arguments against testing for genetic disorders**

- Genetic data about a patient could be shared with or requested by third parties, such as pension or insurance providers, affecting the service people receive from those companies
- Genetic data could be stolen in the event of a cyber security failure
- Customers with a poor understanding of genetics may struggle to make an informed decision about the consequences of using commercial genetic testing services
- The results may be difficult to interpret, which might cause people to worry unnecessarily about potential health concerns
- Vendors are likely to direct concerned consumers to public health services, which increases the strain on public services, especially in the UK where there are insufficient genetic counsellors to meet demand
- People who have undergone genetic testing at birth might not have chosen to have their own genome sequenced.

## Case study: Genome edited human embryos

**Purpose:** Using genome editing to correct a genetic mutation in human embryos that can be passed down from parents. One example of this is a gene that causes a thickening of the heart muscle (hypertrophic cardiomyopathy), which may result in heart failure.

Koya79/iStockphoto



### The global challenge

Cardiomyopathy is one of many inherited conditions that are passed down to a child from its parents. More than 10,000 inherited diseases might be prevented by correcting harmful genetic mutations. Many such diseases are serious, such as cystic fibrosis, Huntington's disease, and breast cancer linked to mutations in the BRCA gene.

### UK facts & figures

- In the UK, cardiomyopathy affects at least one in 500 people of all ages. A mutation in one of several genes can lead to sudden cardiac arrest even in athletes. In some cases the mutation is "dominant" meaning that a single copy (allele) of the abnormal gene is sufficient to cause the problem.
- A recent study suggested that it was possible to use genome editing to correct a dominant mutation in embryos fertilised by sperm from a man with cardiomyopathy. This needs to be verified and further checks on safety must be carried out; therefore it would still be several years before treatments could be available in the UK, if it was deemed to be an acceptable use of the methods.
- It is currently illegal in the UK to implant a genetically altered embryo into a woman's womb; regulators in the US and many other countries also disallow the procedure.

### Arguments made in favour of developing genome edited human embryos

- Allow individuals or couples carrying versions of genes that will definitely give rise to genetic disorders, such as Huntington's disease, to avoid passing them on to their children and to subsequent generations
- Reduce, in offspring, the risk of a disease associated with a specific gene variant, e.g. *BRCA1* and breast cancer
- Reduce the lifetime costs of treating people with genetic disorders
- Research involving edited embryos could improve understanding of the role of specific genes in early human embryo development. This basic knowledge could help to improve IVF success rates, and perhaps reduce miscarriages.

### Arguments made against developing genome edited human embryos

- Genome editing to improve basic knowledge and/or to avoid disease could open the door to use the methods to make 'designer babies'
- The techniques might unintentionally introduce errors that could put future generations at risk
- The money for this research is better spent on developing cures for people living with genetic conditions

### **The alternatives**

- Parents can choose to adopt, or have gamete (sperm or egg) or embryo donation with the loss of a direct genetic connection to the child.
- Potentially harmful versions of genes can often be identified by screening embryos in the lab following IVF (in vitro fertilisation) – a method termed preimplantation genetic diagnosis (PGD). It is then possible to implant only embryos without the abnormal genes into a woman's womb. However, PGD is not always successful, because it relies on having sufficient numbers of embryos to screen and find at least one that is developing well and lacks the abnormal gene(s). Moreover, in some cases it can't be used to avoid a child developing a genetic disease if one parent only has copies of a gene that causes genetic disease, even if the child receives a non-disease causing copy of the gene from their other parent, or if both parents only have disease causing variants of a gene.
- Alternatively, people with a known predisposition to heart disease can be carefully monitored throughout their lives, can avoid over-exertion and can take medication to help regulate their heart rate.

## Case study: Non-heritable genome editing for medical treatments

**Purpose:** Using genome editing to provide new treatments for diseases, such as leukaemia, that have resisted other forms of treatment. These treatments involve making changes to somatic cells, which include all the cells in the body that are not involved in reproduction. As a result, changes made to these cells cannot be inherited by any children of the person receiving the treatment.



Photo credit: YinYang/ iStockphoto

### The global challenge

Leukaemia is the most common childhood cancer, accounting for 30% of all cancers diagnosed in children under 15 years of age in industrialised countries. Five year survival rates (the proportion of children diagnosed with leukaemia who are alive five years after diagnosis and treatment) range from 52.4% in Colombia to 91.6% in Germany.

Established treatments include chemotherapy and bone marrow transplant. For patients in which these treatments have been tried unsuccessfully, there is an emerging treatment that involves extracting a patient's own T-cells (a type of immune cell that targets infected cells within the body, including cancers), genetically engineering them to be more effective at targeting leukaemia and then returning them into the patient.

### UK facts & figures

- There are over 500 new cases of leukaemia diagnosed every year in children aged under 15
- The five year survival rate for these children is over 85%
- Leukaemia is the most common cancer in children under the age of five.

### A genetic technologies example

In 2015 doctors at Great Ormond Street Hospital pioneered a new treatment for leukaemia in an 11 month old girl, Layla Richards, whose cancer had not responded to the conventional treatments. Layla also did not have enough of her own T-cells to use the emergent treatment of modifying her own cells. So in baby Layla's case doctors used T-cells from a donor. They also pioneered a genome editing technique to adapt these cells so they not only targeted the leukaemia but also would not be rejected by her immune system or affected by the chemotherapy drugs.

The treatment effectively targeted Layla's leukaemia and two years later it has not returned. The same technique has since been used to successfully treat another infant, although further successful trials would be required before the treatment is made more widely available. Both children will be monitored over the long term to check for complications from the treatment or the return of the cancer.

### **Arguments in favour of developing somatic genome editing treatments**

- Genome editing is opening up new treatment opportunities for otherwise intractable diseases, including certain types of cancer and HIV, as well as genetic diseases such as cystic fibrosis
- Editing donor cells opens up the possibility for cheaper, readily available genetic therapies for leukaemia.

### **Arguments against developing somatic genome editing treatments**

- Long term efficacy and possible side-effects of these treatments are unknown
- Compared with some conventional treatments, genome editing is currently very expensive
- Some somatic treatments might also have the potential for enhancing basic human characteristics such as height or strength.

### **The alternatives**

In this specific case study, the somatic genome editing treatment was used where all available alternatives had already been tried.

## Case study: Reducing the risk of vector-borne diseases

### The global challenge

Vectors are animals, like mosquitoes, that carry disease-causing pathogens from one person to another. Vector-borne diseases are carried by these organisms and include malaria, dengue, Zika and Lyme disease. There are around one billion cases of vector-borne diseases worldwide each year, resulting in more than a million deaths. Malaria, dengue and Zika are carried by mosquitoes, while Lyme disease is carried by ticks.

Photo credit: iStockphoto



### Approaches to disease vector control

Common approaches to reducing the risk of a vector-borne disease are using pesticides to kill the vector and preventing vectors from biting people by encouraging vulnerable people to sleep under bed nets, covering their skin with clothing and wearing insect repellent. For short time-periods, people can take preventative medicines for some diseases, including malaria. Vaccines for malaria and dengue are in advanced stages of testing but are only partially effective. Malaria and Lyme disease can be treated if they are caught quickly enough, but there is no specific treatment for dengue.

### A genetic technologies example

An Oxford-based biotechnology company has genetically engineered mosquitoes to produce offspring that cannot reproduce. Mosquito eggs were genetically engineered, by injection in the lab, to contain a fatal gene. Male mosquitoes born from these eggs are kept alive using an antidote while females are killed. These males are then released into the wild to mate with wild females before dying. The offspring of the wild females that had mated with the engineered males inherit the fatal gene, which means they die within a couple of weeks, before they can breed. This should reduce the target mosquito population. Because both the engineered mosquitoes and their offspring die, the effect of these interventions reduces over time and they need to be repeated regularly to maintain their effectiveness.

Scientists are also working on genetic interventions to reduce the population of disease-carrying mosquitoes using 'gene drives', which could deliver long-lasting population reductions.

### UK facts & figures

- The UK is home to 34 native mosquito species, none of which carries malaria or dengue
- However, there are more than 20 species of tick in the UK, several of which carry Lyme disease
- In the UK, around 3,000 people every year contract Lyme disease from ticks.

### **Arguments in favour of genetic engineering approaches to disease vector control**

- The continuing burden of disease and death toll from diseases such as dengue, malaria, Zika and Lyme disease demonstrate that existing interventions are not completely effective. Genetic approaches offer the possibility of a new class of interventions to add to existing ones
- The costs of current prevention methods are too high to be used effectively in some countries, whilst the cost of current treatments are unaffordable to some people. Genetic approaches may alleviate this pressure on health systems by reducing the costs of prevention and the costs of treatment
- In the case of mosquito-borne diseases, the mosquito populations are evolving resistance to the existing chemical methods of control. Genetic approaches could prevent some of these resistant mosquitoes from reproducing and so prolong the usefulness of current methods
- Where genetic approaches are used instead of chemical methods of control, negative impacts on plants and other animals from using these insecticides could be reduced.

### **Arguments against genetic engineering approaches to disease vector control**

- The consequences for local ecosystems of introducing genetically engineered disease vectors to the environment could be difficult to predict and control, and some effects could be irreversible
- How effective genetic engineering interventions can be is still the subject of research, and disease vectors might also develop resistance to them
- The accidental release or escape of animals involved in gene drive research could have permanent unintended consequences
- The improved technological understanding gained from developing gene drives for vector control purposes could make it easier to develop gene drives for illegal or unregulated purposes, although this would depend on developing new gene drives as it's not possible to use the same drive in different species.

## Case study: Meeting the need for donated organs

### The global challenge

In 2014, around 120,000 people received organ transplants worldwide. However, it is estimated that more than one million people would have benefited from an organ transplant, if it had been possible. The most common organ transplants are kidney, liver and heart. In developed countries, one of the major limitations on meeting demand for organ transplants is a lack of appropriate organs for donation. There are both international networks for the ethical sharing of organs and an international black market in organs for transplant, especially kidneys.

Photo credit: Clare McLean for UW Medicine, Creative Commons



### Current approaches to meeting the need for donated organs

The most common approach to increasing the availability of organs for donation is running public awareness campaigns. Some countries, like Wales, operate an 'opt-out' approach to organ donation, so people have to remove themselves from the list of organ donors rather than add themselves to it. For kidneys, because people can donate one of their two kidneys and still survive, some people argue for a regulated market in which kidneys would be sold legally to make money. Such a market already exists in Iran.

### A genetic technologies example

Pig organs are roughly the same size and do the same jobs as human organs, which means they are good candidates for human organ transplants. Valves from pig hearts are already used in people. However, pig cells carry retroviruses as part of their DNA that make normal pig organs potentially dangerous to humans. Using genome editing, scientists have demonstrated it is possible to make this viral DNA inactive in pig cells to stop it being infectious. They also demonstrated that the genome editing had not had any unintended effects and used the edited cells to develop pig embryos. From these embryos, fifteen piglets were still alive at the time the research was published and scientists continue to monitor them for any negative effects of the procedure.

Whilst this is a necessary step towards making pig organs that are suitable for use in humans, there are further practical, safety and ethical concerns that would have to be addressed before pig organs could be transplanted into people.

### **UK facts & figures**

- There are currently 6,500 people on the NHS's organ transplant waiting list
- Last year, nearly 500 people died while waiting for an organ transplant
- In the UK, it is particularly difficult to get transplant organs for people in minority ethnic groups, from which there are fewer potential donors.

### **Arguments in favour of using genome edited pig organs**

- If pig organs were made suitable for use in patients needing an organ transplant, this would reduce the deaths associated with waiting for organ transplants
- As people waiting for an organ transplant need medical care, if increasing the supply of suitable organs for transplant reduced waiting times for organs, this would reduce the pressure on and costs to health services

### **Arguments against using genome edited pig organs**

- The long term consequences of the technique (CRISPR-Cas9) used to edit the DNA in pigs are unknown
- Some people will object to animal organ transplants for animal rights or religious reasons

## Case study: Reducing the negative ecological effects of fish farms

### The global challenge

Fish farming is an increasingly important source of fish for human consumption, providing nearly 50% of the fish consumed by people globally, compared to 9% in 1980. However, farmed fish are often fed using wild-caught fish, and taking lots of wild-caught fish from the oceans has negative consequences for ocean ecosystems, with 90% of the world's fish stocks classified as fully or overfished by the UN.

Photo credit: Ingrid Taylor/ Creative Commons



### Approaches to reducing the negative ecological effects of fish farms

These negative effects can be reduced by increasing the use of vegetable-based proteins as food for farmed fish, and farming non-carnivorous fish such as tilapia that do not require wild-caught fish for food. Further opportunities for minimising the impacts of fish farming include changing human diets to reduce the demand for farmed fish, and reducing food waste.

### A genetic technologies example

25 years after it was first developed, a variety of Atlantic salmon engineered with genes from another salmon and genes from another fish species that increase how quickly it grows went on sale in Canada in August 2017. These genetically modified (GM) salmon require less food than unmodified salmon to reach a desired size and weight. They have also been engineered to be sterile to reduce the risk of interbreeding with wild salmon if the farmed salmon escaped.

### UK facts & figures

- Salmon provides 0.6% of the average person in the UK's daily protein intake
- No GM salmon is currently on sale in the UK
- Current UK regulations require all food sold in the UK consisting of GM organisms or containing ingredients produced by GM organisms to be clearly labelled as GM.

### Arguments made in favour of developing GM salmon

- Reduce the amount of wild-caught fish required to produce a given amount of farmed fish
- Reduce production costs for aquaculture companies

### Arguments made against developing GM salmon

- Escaped GM salmon could breed with wild salmon if the intervention to make them sterile was not completely successful
- Escaped GM salmon could outcompete wild salmon because they need less food and grow more rapidly
- If lower production costs enable an increase in the total amount of salmon farmed, then this could lead to an increase in the total amount of wild fish caught to feed them.

## Case study: Reducing vitamin A deficiency

### The global challenge

Vitamin A deficiency is the leading cause of preventable blindness in children and increases the risk of disease and death from severe infections. In pregnant women it can cause night blindness and may increase the risk of maternal mortality (the death of women during pregnancy or within 42 days of giving birth). An estimated 250 million pre-school children worldwide are vitamin A deficient. An estimated 250,000–500,000 vitamin A deficient children become blind every year, with half of these children dying within 12 months of losing their sight because their deficiency is so severe.

Photo credit:  
Alpha/Creative Commons



### Approaches to reducing vitamin A deficiency

The most common way to reduce Vitamin A deficiency is by providing vitamin A supplements. These should be provided every four to six months in all children aged six months to five years at risk of vitamin A deficiency, and cost US \$0.04 per child per year. Many countries where children receive vitamin A supplements also have programmes to fortify foods with vitamin A. Other initiatives seek to increase the variety of foods available to people with nutrient-deficient diets by encouraging people to grow fruit and vegetables at home.

### A genetic technologies example

Rice can make up the majority of food that children suffering from vitamin A deficiency eat in some countries. Scientists have therefore developed, using GM technology, a type of rice, labelled Golden Rice, which provides more dietary vitamin A. The first Golden Rice was developed in 1999 using philanthropic funding. The intellectual property was then given to Syngenta, an agro-chemicals company, on the basis that it was made freely available for 'humanitarian uses'. Syngenta can charge for uses that do not qualify as humanitarian. There are currently trials to develop locally adapted varieties of Golden Rice in sixteen national rice research institutions including in Bangladesh, Vietnam, the Philippines and India.

### UK facts & figures

- Vitamin A deficiency is not a significant problem in the UK. The most significant nutrient deficiency is for vitamin D which affects 30–40% of the population during winter
- An increasing proportion of the UK's overseas development budget is spent on improving nutrition (from under 6% in 2010 to over 10% in 2015).

### **Arguments made in favour of Golden Rice**

- Supplement programmes do not reach all children all of the time, so increasing dietary sources of vitamin A is still important
- Increasing dietary sources of vitamin A provides a lasting solution whereas supplement programmes require continuous investment
- Since GM foods were first eaten by people in the 1990s, over a trillion meals that include GM food have been eaten with no evidence of negative health effects.

### **Arguments made against Golden Rice**

- Golden Rice provides a solution to vitamin A deficiency rather than addressing the underlying causes of poverty and poor diets
- Despite almost 20 years of research and development there are still no commercially available Golden Rice varieties
- Golden Rice varieties developed in Europe are culturally or environmentally unsuited to the countries where they are needed
- Despite licence requirements that mean Golden Rice has to be provided free to farmers earning less than US \$10,000 per year, Golden Rice varieties are still the intellectual property of Syngenta so growing them increases the influence of large agribusiness in local supply chains
- Some people are concerned about negative health effects from eating GM foods.

## Case study: Preventing fungal disease in plants

### The global challenge

Diseases of plants and trees caused by fungi and closely related organisms, such as wheat rust or potato blight, are the fastest growing cause of crop diseases. Historically these diseases have been devastating, leading to the Irish potato famine in the nineteenth century for example. Nowadays fungal diseases of the top five food crops worldwide – rice, wheat, maize, potatoes and soybeans – destroy at least 125 million tonnes of these crops every year (about 4% of the total production). The economic cost of these losses for rice, wheat and maize have been estimated at US \$60 billion. Whilst fungal diseases affect crops everywhere, they are disproportionately damaging in low-income countries where people rely more on staple food crops.

Photo credit: Sandra Jensen, Cornell University, Bugwood.org /Creative Commons



### Approaches to preventing fungal disease

The most common way of controlling fungal diseases is spraying fungicides – chemical compounds or organisms like bacteria that kill fungi or their spores. However, many fungicides are only effective at preventing outbreaks of fungal diseases rather than treating infected plants. Some fungicides are certified for use in organic agriculture.

Plants have their own defences against fungal infections, so another approach is to selectively breed new crop varieties that are resistant to fungal infections. For example, in August 2017, the Dutch company Solynta announced that it had successfully bred a potato variety resistant to late blight, the disease that caused the Irish potato famine.

A common problem with fungal infections is that fungi evolve rapidly, so effective fungicides or resistant crop varieties can quickly become ineffective. Farming practices, such as how far apart plants are planted and removing dead plant material from fields, are also important for preventing fungal infections.

### A genetic technologies example

British scientists have developed a genetically modified (GM) variety of the Désirée potato that is resistant to late blight. They did this by introducing a gene from a wild South American potato variety that activates defence systems within the plant to resist blight. These modified potatoes have successfully resisted blight in UK trials, but are not grown commercially here. The scientists have since licensed the technology to an American potato company, Simplot, which has secured regulatory approval for the commercial production of GM blight-resistant potatoes in the USA and Canada.

### **UK facts & figures**

- The UK produces 6 million tonnes of potatoes a year and late blight is the most significant threat to this crop
- Farmers can spray their crops up to fifteen times a season with fungicides to prevent late blight. Prevention measures and crop losses cost British farmers around £55 million per year
- Blight-resistant varieties of Sarpo potatoes have already been selectively bred using conventional methods and are commercially available in the UK.

### **Arguments made in favour of GM blight-resistant potatoes**

- Blight-resistant plants reduce the need for fungicides, which are expensive and can be environmentally harmful
- Introducing blight resistance using genetic engineering as opposed to conventional breeding is faster and likely to have fewer impacts on other valuable properties such as yield and flavour
- If evolution of the fungi that cause infection mean engineered resistance is no longer effective, then it is relatively easy to insert new resistance genes. It is also relatively easy to introduce multiple resistant genes at the same time meaning that the resistance is likely to be effective for longer
- There are no wild plants related to potatoes in the UK that the engineered trait could be accidentally transferred to. If the trait were transferred to non-GM potatoes, then the way potatoes are propagated from tubers rather than from seeds mean this should not affect future crops.

### **Arguments made against GM blight-resistant potatoes**

- The process for developing and trialling GM varieties of crops is more expensive than using conventional breeding
- The market for GM potatoes is uncertain given general consumer concerns about negative health effects from eating GM foods and the involvement of large agribusinesses in developing GM crops.

## Case study: Developing new medicines more cheaply

### The global challenge

The development and manufacture of medicines can be really expensive. This is especially true for an emerging class of medicines, (biopharmaceuticals) that are made using living organisms and tend to comprise larger, more complex molecules than medicines made through combining and reacting chemical raw materials. Biopharmaceuticals are being developed for conditions with no existing treatments, such as Ebola, or for which existing treatments are inadequate, such as cancer.

In the UK, the NHS already spends a large portion of its budget on medicines. In other countries without national health services there is a large cost to individuals: either to those who become ill or to those who pay insurance premiums. In some cases people cannot afford to get the treatment they need.



Photo credits: iStockphoto

### Approaches to manufacturing new medicines

Historic production methods for many biopharmaceuticals involved extraction from animal tissues. Now they are typically produced by inserting human, animal or plant genes into bacteria, yeast or animal tissue cultures (animal cells kept alive and functioning outside of the organism which they originally came from). These engineered organisms or tissue cultures are then kept alive in a contained environment.

### A plant genetic technologies example

Tobacco plants have been genetically modified (GM) to produce some of these biopharmaceuticals. These include 'recombinant human proteins', which can be used to treat conditions such as diabetes and growth disorders, or antibodies, which can be used in treatments for HIV and Ebola. Tobacco plants can either be permanently or temporarily engineered to produce biopharmaceuticals.

Before they can be used by people, plant derived pharmaceuticals have to be extracted and purified, although there are proposals to modify food plants to enable 'edible vaccines'.

### UK facts & figures

- Almost half of all UK adults take prescription drugs on a weekly basis
- The NHS spent 14% of its total budget on medicines in 2015/16: £17 billion from a total of £116 billion
- GM plants are not currently used to produce materials for medicines in the UK, or Europe, but in 2011 the UK's Medicines and Healthcare products Regulatory Agency (MHRA) approved a clinical trial involving antibodies against HIV derived from tobacco grown in greenhouses in Germany.

### **Arguments made in favour of using GM plants to develop new medicines**

- Reduced cost of producing biopharmaceuticals and increase the scale of production
- Produce new classes of medicines that can treat previously untreatable diseases or have fewer side effects than existing treatments
- Produce vaccines that can be swallowed rather than injected.

### **Arguments made against using GM plants to develop new medicines**

- Where GM plants are grown outdoors, engineered genes may be transferred from GM plants to related plant species, especially if food crops like maize or rice are used to produce biopharmaceuticals
- With current technology, the extent to which individual GM plants produce a biopharmaceutical cannot be controlled, so getting the right dosage could only be achieved with post-harvest testing
- Unlike microorganism or animal tissue cultures, standardised protocols for purifying plant-derived pharmaceuticals have not yet been developed, and a different protocol would be required for each plant type
- Animals eating these plants unknowingly would experience the effects of the drug in question.

## Appendix 8. Quantitative technical note and results

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### 1. Note

The survey was conducted from 1<sup>st</sup> to 13<sup>th</sup> November 2017 with a nationally representative sample of 2,061 adults across the UK using a panel approach through which all respondents were engaged online. The following data tables present the core survey data for the full population of interest unfiltered by age, faith or other demographics. The exception to this is when analysis showed significant differences in relation to respondents' age which have been drawn on as a finding in the main report. Where this applies the relevant data tables relating to age are included under the core survey data. Where stats do not sum exactly this is due to rounding errors.

Where results show less than 2,061 responses it indicates the total number of respondents who completed the question. This is shown as 'base' on each table where less than 2,061 respondents completed the question. This could only occur when a response was not mandatory. Where stats do not sum exactly this is due to rounding errors.

The confidence or significance level for this study is 95% meaning that we are 95% certain that the quantitative findings represent the views of the UK population. There is a  $\pm 5$  confidence interval meaning that for any percentage figure given, 5% less or 5% more in the whole UK population might have responded in the same way. The survey questions cover attitudes towards genetic technologies in general as well as attitudes towards specific applications.

### 2. Core survey data

#### 1. Age

	%	No.
Less than 18	0%	0
18 - 34	31%	635
35 - 54	35%	726
55 - 74	23%	494
75+	11%	206
	Base:	2061

#### 2. Are you?

	%	No.
Male	48%	983
Female	52%	1078
	Base:	2061

#### 3. Where do you live?

	%	No.
South	44%	907
Midlands and Wales	21%	433
North and Scotland	32%	659
Northern Ireland	3%	62
	Base:	2061

4. Which of the following, if any, would you say you do at least once a month? [Please respond to all the answers that apply to you]

	%	No.
Watch or listen to documentaries about science, health, nature or the environment on television or radio	56%	1161
Watch or listen to documentaries about science, health, nature or the environment online	31%	645
Read articles about science, health, nature or the environment in published newspapers or magazines	31%	631
Read articles about science, health, nature or the environment online	34%	711
Read science-fiction novels	20%	418
Watch science-fiction films	38%	783
I don't do any of these things once a month	13%	269
I don't know if I do any of these things once a month	5%	113

5. How interested, if at all, are you in global challenges such as sustainable energy, climate change, famine, disease and over population?

	%	No.
Very interested	31%	631
Fairly interested	49%	1012
Not very interested	12%	256
Not at all interested	5%	106
I don't know	3%	56
	Base:	2061

6. How interested, if at all, are you in the role of scientific developments to address those challenges?

	%	No.
Very interested	32%	659
Fairly interested	48%	990
Not very interested	11%	226
Not at all interested	5%	112
I don't know	4%	74
	Base:	2061

7. Please rank the top five sources you think would give you the most trustworthy information about scientific developments to address global challenges. Your first click is the source you consider most trustworthy.

	Ranking	%	No.
Documentaries about science, health, nature or the environment on television or radio	1	43%	730
	2	18%	300

	3	18%	310
	4	15%	250
	5	7%	121
		Base:	1711
Friends, family and neighbours	1	35%	234
	2	23%	152
	3	15%	103
	4	16%	106
	5	12%	80
		Base:	675
Government information on science, health, nature or the environment	1	18%	270
	2	28%	417
	3	23%	346
	4	17%	257
	5	14%	212
		Base:	1502
Information found on social media including from sources such as Twitter, Facebook and LinkedIn	1	7%	42
	2	24%	151
	3	26%	160
	4	31%	191
	5	12%	73
		Base:	617
Information found online including from sources such as Google, Wikipedia and YouTube	1	6%	50
	2	13%	118
	3	21%	185
	4	22%	195
	5	38%	329
		Base:	877
Lectures, public events given by academics, researchers or scientists	1	26%	371
	2	28%	399
	3	18%	263
	4	14%	201
	5	14%	201
		Base:	1435
Online or in print articles written by experts in science, health, nature or the environment	1	21%	292
	2	22%	302
	3	21%	297
	4	20%	280
	5	15%	211
		Base:	1382
Online or in print articles written by journalists on science, health, nature or the environment	1	2%	20
	2	11%	94
	3	20%	169
	4	28%	235
	5	39%	325
		Base:	843
Online or in print articles written by other people on science, health, nature or the environment	1	5%	38
	2	11%	79
	3	20%	139

	4	27%	193
	5	37%	262
		Base:	711
Statements made by religious leaders	1	16%	14
	2	6%	6
	3	15%	14
	4	24%	22
	5	39%	36
			Base:

8. How interested, if at all, are you in genetic technologies? (By genetic technologies we mean anything to do with understanding, making or adapting genetic material, but excluding conventional breeding/reproduction).

	%	No.
Very interested	24%	489
Fairly interested	46%	956
Not very interested	20%	404
Not at all interested	7%	136
I don't know	4%	76
	Base	2061

9. Have you seen/ read/ heard (on the news, in a paper or on social media for example) any information on genetics or genetic technologies in the last month?

	%	No.
All ages		
Yes	28%	568
No	72%	1493
	Base	2061
18-34 year olds		
Yes	39%	246
No	61%	389
	Base	635
35-54 year olds		
Yes	25%	185
No	75%	541
	Base	726
55+ year olds		
Yes	20%	138
No	80%	562
	Base	700

What did you see/ read/ here [please list here – written by respondents in their own words]

A BBC article on altering some of the gene coding on some crops in the USA
A child in Germany having genetically grown skin grafted onto his body
A debate on the ethics of genetically modified crops
A documentary about The Netherlands. Most of that country lays underneath the sea, so it means that if some dams, or more of the ice on the north pole is melting, The Netherlands can be decreased into a little country.
A documentary discussing the moral dilemmas of eradicating genetic diseases without absolute consent from the populous.
A girl who had skin problem and had about 60 percent of her skin coming off. The hospital took a part of her skin and removed the faulty gene and replaced it with stem cell and covered her skin and her skin healed and the fault have not come back
A lot of different topics
A news report on the possibility of reversing type 1 diabetes. Also I read a report on fibromyalgia
A review of Monsanto damaging the soil with Round Up and the only crops that can now grow on the land are genetically modified ones
A simplified explanation on the manipulation or editing out of undesirable genes from the cell's DNA
A very interesting documentary about how gene editing works
A young boy with a skin disease who had a skin sample DNA reengineered and grown to replace the skin that was damaged
About a 7 year old boy who has a skin graft to cure his EB using his own skin - adapted and then grown correctly
About a child that received transgenic skin, because of a disease.
About a genetic translocation on the web to do with a disability in children. It is fascinating because I have experienced problems.
About a new bigger planet in a distant solar system 33 times bigger than Jupiter
About AI and splitting genes if all they say went starting a speak is praise be to god well all the stupidity is against the bible
About disease and how genetics affects and research round that topic
About DNA
About gene editing being used to cure a young boy with skin problems
About gene splicing techniques being used to help cure a disease
About genetic changes in wheat seeds, for example Monsanto Company.
About genetic modifications, the reasons for doing it, its pros and cons.
About genetics
About how designer babies are going to be a reality in the future.
About new skin being grafted onto a child with very fine 'butterfly' skin, due to a genetic condition.
About pest resistant genetically modified crops
About the WM eye condition
About test tube babies
About woman's genetics and how it affects her getting old and about food genetics and modification.
Adverts
Advert for DNA ancestry
All sorts
Along similar lines to the video at the start of this survey. About how research into genetics are improving and various uses. It didn't give negatives though so it was a little biased
An article about CRISPR which showed how ordinary people could do some amazing things
An article about designer babies
An article about using gene technology in a bid to eradicate serious health conditions
An article in a newspaper

An article in The Telegraph which I followed up online
An article on genetic engineering for elevating human consciousness
An article on SANDS website about genetic tendencies in stillbirth/miscarriage
An article online about the way scientists edit or manipulate certain genes
Ancestry are genetically tested people to see where they are from
Article about a boy who had a mutant gene that caused skin problems
Article about food with genetic technologies
Article about GM crops in the context of post-Brexit trade agreements
Article about mixing a pig and a human's DNA.
Article on gene editing to cure skin disorder in young boy
Article on gene editing,(CRISPR) article on growing new skin for young boy suffering from rare genetic skin disease
Article on GM crops and how to improve food production during drought.
Article on the news about taking a small section of skin from a child with "butterfly" skin syndrome, which was genetically modified then used to grow "new" improved skin that was transplanted back onto the child - very successfully.
Articles about CRISPR gene editing Articles about children born from 3 genetic parents (Mitochondrial repair)
Articles regarding the new testing for Downs Syndrome being offered to pregnant women
awesome
BBC Click. Very interesting ,on all reports
BBC News about genetically engineered skin to cure a child's inherited fatal skin disorder
BBC site
BBC website
Big bang
Boy gets brand new skin with gene therapy
Boy receives new skin through gene therapy
Boy with a skin disease who had the DNA changed so that it could be grown in a lab and used to re-cover his body
Boy with rare skin disease gets new skin using gene therapy and stem cells
changing genes
Child cured of potentially fatal skin condition using gene therapy
Chinese breakthrough recently, but can't remember the specifics. Downs test developed - in today's paper
Climate devolution and genetic mods
CNN, Readers' Digest, BBC
Correction of genetic errors by using 3 parents
CRISP technology,
Crops genetically modified
Daily Mail had article about using stem cells from knee to grow new ones which can help osteoarthritis
Daily Mirror
Designer Babies
Development in cancer research
Developments on the way we can cut genes to change them
DNA
DNA related issues
DNA testing to help with ancestry searches
DNA, embryos and diseases as well as plants and animals
Drosophila flies can have legs growing in place of their antennae
Drug testing on animals normal and genetically modified
Editing genome for child with skin disorder
Effects of modification to health

EPIGENETICS PIECE IN NEW SCIENTIST
Falsified data. Compromised DNA testing
Friend put an link on social media to some journalist work
From YouTube
Gene editing to get rid of breast cancer and other disease genes
Gene Editing using the skin from a child who's own skin lacked an epidermis to create a new skin with an epidermis that could be grafted back onto the child. - BBC news
Gene editing, genome mapping, genetic therapies
Gene editing, telomere repair
Gene modification
Gene splicing and rewriting to eliminate bad genes
Gene therapy
General developments in curtailing hereditary health issues in animals (including us!) & plants
Genes
Genes, kids genes are inherited by their mums and dads
Genetic code generation
Genetic development of food
Genetic editing
Genetic generation
Genetic modification of animals for health purposes, e.g. growing or using animal organs for human transplant
Genetic modification on curing diseases
Genetic modification pros and cons
Genetic screening for hereditary diseases
Genetic screening making it possible to remove faulty genes from passing down to a baby
Genetic selection and mutation in food industry. Research on a new antibiotics
Genetically altering animals to make them compatible with humans with allergies
Genetically modified apples in USA
Genetically modified apples that don't brown
Genetically modified food. Designer babies
Genetically modified skin for child who had terrible skin condition (don't remember name - a sort of painful psoriasis I think). I think the child's skin cells were cloned, then "edited" and then skin grown to graft onto body
Genetics could be very helpful in the future if successful research and development is carried out
Genetics fruits and vegetables are available in market
Genetics is the new tool in the battle against wheat pests
Genomic update
Growing skin to help a child with a rare skin condition
Heard about genetic material and how it can be used to treat cancer
Heard how scientists are currently modifying the DNA of mosquitos to prevent them carrying malaria
Heard on the radio regarding gene therapy
High precision
How different genes determine your health
How gene technology can save lives
How genes can be manufactured
How genetics could help create designer babies by changing genes
How it can affects
How many diseases can be prevented in the future through the human genome programs
How the split the a DNA section was replace with better form of DNA
How to cut DNA strands using a new technique
How to repair fragile skin by taking a sample injecting a gene to cure and transplant back to the donor

Human embryos edited to stop disease - BBC News
Hybridisation
I saw a video on YouTube about genes
I can't remember the exact genetic illness but I saw television content about the advancements being made in gene therapy that may eradicate certain diseases in the foreseeable future. I have also read several articles in relation to gene mutation and manipulation in plant species to maximise yield, eradicate disease and make them more resistant to pests. There were also articles relating to how this could change agricultural practices in various areas of the world, and the impact on food poverty.
I did a topic on designer babies for A-Level Ethics
I didn't really understand too much of it, but it was about the positive benefits to human health of modifying genes.
I have heard of genetic engineering in embryos to weed out inherited diseases, in medical research to cure diseases, also of genetically engineered crops
I have read about genetic technology using Crispr.
I have read articles and books and spoken to a lecturer at university about gene therapies and cryopreservation.
I have read Sapiens and Homo-Deus
I Have Seen About These All Things Gained Knowledge About These Things
I heard a radio interview about gene therapy and childhood illnesses
I heard about eradicating Downs Syndrome via gene therapy
I heard about the plants that are being modified so they could grow in places where they do not normally grow, like say in the desert.
I heard not only about the benefits of this technology, but also why and how it can be used in the modern world to treat diseases
I heard on the radio about the new medication for cf and the drug trials that it involves also on dementia and new drugs trials
I heard that it's very interesting and needs to be talked about a lot more than it is right now. I feel like people don't understand it and therefore don't appreciate it enough
I just read today about doctors saving a child's life by creating new skin for him. The disease he had offered virtually no chance of survival
I read about 3 parent babies, to prevent the spread of Mitochondrial disease to the offspring
I read about designer babies, and the ethical problems behind it
I read an article about a new cancer therapy in the United States which involved altering the patient's cells
I read an article on BBC Health about base editors and their ability to modify the structure of the 4 key elements of DNA to correct errors that could lead to disease
I read several scientific articles (written by scientists) on this topic.
I read something about animal genetics
I read something about the flu virus also the zika virus which seems to have gone out of the media
I read that it could be a great solution for curing DNA-transmitted diseases and many others. Also I read that it could make fruits flawless, making them protected from many diseases.
I saw a video of a man with downs syndrome saying scientists are developing technology to stop people being born with it. He expressed that this is wrong to do as his life has been worth living
I saw an online social media argument between supporters and opponents of using GMOs in food. It included an argument about the merits of "Golden Rice."
I saw something in the newspaper can't remember the details
I saw that it was interesting
I study animal science
I teach a unit at school based around Jurassic Park. In this unit we research the history and current developments in genetics. This includes selected extracts from scientific papers as well as online resources that I have researched and selected as appropriate from BBC, nature.com etc.

I think I was something to do with genetic testing for a particular disease and regarding using embryos to select the healthiest one and preventing the particular inheritable disease
I was reading a science magazine and saw something about designer babies and gene splicing
I watched a Ted talk about how science is using genetics to combat things like cancers and other medical problems, which I found very interesting and enlightening about the possibilities genetics has in the coming years
I watched a video online about changing DNA
I watched some documentary about future data storing in DNA
I watched some great scientific documentary movie on discovery channel recently.
I went to a lecture about a movie Gattaca. The movie is about how humans that have not been genetically modified receive some class of racism from the modified ones and the lecture was based in the possibilities that this could happen to us in the next decade as result of the achievements that science have done in the genetic modification area
I'm a statistician and I work with researchers who are interested in understanding R-gene resistance to pathogens so I read a lot of academic papers on the subject. I've also heard a number of programs on BBC radio 4
I'm a student and have been reading about heritability of intelligence in both textbooks and research articles, as well as newspaper articles reviewing twin studies and the claim that the genes that govern intelligence have been identified.
Identifying genes which cause particular diseases
Improvements on gene modification in human medicine
In a newspaper
In the Guardian
In the library it was interesting, learning and exciting
Increasing use of gene editing to promote health
Info on cures for diseases
Information about the policy environment for the application of genetic technologies to plants and animals;
Information on DNA and how it can identify people
Interesting what genes can do and alter of genes in the order. I think it looks good for the future good medical easy to understand
It is one of the guiding socio-economic principles
It was a newspaper feature on a possible dystopian future should our increasing knowledge re genome editing be misused. Very simplistic.
It was about a boy with a skin disorder which left him with raw skin and doctors thought he would die. But they took a sample of his skin, changed it and grew it in a lab and put it back on him and now he is better
It was about GM crops
It was all about genetics and what they do for us
It was an article about GM foods.
It was something to do with using animals to treat conditions
It's about in-vitro fertilization or test tube baby
It's one the most informative and good one and i like it very much
Just a recent report on the a specific research project involving genetics
Just about DNA
Just about it being used for designer kids
Just basic facts about gene tech and the different ways it could be used
Kurzgesagt channel on YouTube. Startalk channel on YouTube
Latest warnings about robots taking 10 million jobs
Learnt about my family genetics
Lecture at university regarding CRISPR technology and recombinant DNA
Lecture on evolution
Link to cancers

Links to diseases
Magazines and TV: National Geographic and Discovery Channel/Scientific, how to affect into genetic code DNA, to help the people for their health
Making heart tissues in a laboratory
Malaria affect baby
Medical use to heal a congenital skin condition
Medicines targeted due to genetic typing
Mental Health
MIT Open Courseware lecture on Genetics
More negative information about the use of GMOs in agriculture - they're doing more harm than good.
Most recent was butterfly skin cure
Museum exhibit about CRISPR
Nanotechnology
National geographic, discovery channel
New advances in technologies taking place
New breakthroughs
New phone technology's that was very inspiring.
New research about cancer treatment and new therapy
News articles about gene editing to remove some genetic illnesses
News items on gene editing. Program on viability of cloning mammoths.
Newspaper articles about what they are developing especially on animals with new limbs. Articles about whether it is right to create designer babies?
News story about genetic editing to help cure disease
News story about German boy with damaged skin
Not a lot really, apart from latest developments and how it will make your life easier
Not sure something about engineering a method to grow skin
On a tv program they were looking at genetic programming and discussing changing this in order to combat various diseases
On DNA technology
On how genetics or genetic technologies work, or on how they can change everything in this world.
On Radio 4
On the Naked Genetics podcast about someone who had donated his genome for scientific research. He was willing for the results to be freely available.
On TV about reversing childhood leukaemia
Ongoing gene therapy investigations to develop methods to cure diseases such as sickle cell anaemia using stem cells.
Online article
People can choose the child they have
Positive and negative arguments
Possibility of designer babies
Potential merger of agribusiness specialising in genetically altered crops creating market dominate and potentially unregulated situation
Program about genetic manipulation to eradicate malaria by changing mosquito DNA
Progress in achieving new ways of altering genes in unborn babies
Quality science
Radio programme on IVF
Radio talk on using CRISPR
Read BBC
Read some reports on the societal/legal issues surrounding the use of genetic editing in humans to erase the possibilities of babies being born with particular chronic disease or conditions.
Read something about altering mosquitoes to eradicate malaria

Reading about the negative side and unscrupulous people trying to create designer babies which is a big worry because people these days are so non-trustworthy and have their own hidden agenda for almost everything.
Reading articles appearing in newspapers, books, lectures etc.
Recently - a cure for a child with a rare illness
Regarding DNA
Relevance of taking DNA tests
I remember a TV item on the news but not what it was about
Request I made to the Geno programme relating to how far past generations DNA relate to current generations
Saw a documentary on TV
Saw the video on it
Say we need to help the place to save it with recession and all the other things
Science can change our lives
Scientific research in humans for health in a positive way
Scientific research on cancer involving HPV
Scientists have grown new skin for a boy with life threatening skin disease
Scientists grow replacement skin for boy suffering devastating genetic disorder
Scientists have eradicated a gene that produced Downs Syndrome in Finland
Scientists trying to find ways to stop genetic illnesses
Scientists used healthy cells from a patient to replace most of their skin, curing the patient of a disease that would cause extreme pain otherwise
Scientists will be able to better target cancer cells
Similar information to the video just shown
Something about a possible cure for cancer; I don't remember the details.
Something about CRISPR. Didn't have time to read the entire article.
Something about growing skin
Something in the paper about genes
Stephen Hawking
Studied about gene in primary school
Taking out certain genes to stop hereditary diseases
Talking about DNA
That genetics decide the whole personality of a child
That many diseases can be avoided in your children through genetics.
That they are testing to use stem cells to cure Parkinson's disease
The ability to remove harmful DNA
The conventional screening test for Down's and other chromosomal disorders.
The development of genetic research & applications in treating people with severe skin disorders
The genetic manipulation of crops to prevent diseases, resist drought etc. by the company Monsanto
The innovation for cancer
The processes
The scientific experience of DNA and genes.
The stranger the better and good progress is good - thinking out the box
The tampering with seeds marking out the danger of one/few companies owning all food growing resources
The use of gene therapy to treat diseases
There have been some programmes on the World Service talking about the problems associated with genome editing
There was an item about a genetic test that could now be undertaken, testing for Down's Syndrome in unborn babies
They are going to do that with the green stuff
They were discussing gene manipulation to make crops withstand pestilence

They were talking about GMO's
Things about genetic modification in plants
Things about IVF and cloning and medical research
To prevent future diseases by acting in a healthy manner
University lectures, scientific reading
Using genetic technology to grow cell cultures for transplants, and in artificial meat growth from somatic stem cells
Using it to help animals become resistant to certain diseases
Was a TED lecture about CRISPR
Watching Blue Planet 2
We were learning about genetic modification through snipping a part of DNA out using an enzyme, and replacing it with a gene with the desired effect.
What is gene editing?
Wired posted a video of an expert explaining CRISPR to in 5 levels of difficulty; child, teenager, undergraduate, graduate and expert
Young boy with genetic skin condition received skin grafts: skin grafts were genetically altered skin grown in lab.

10. How interested, if at all, were you in what you saw/ read/ heard on genetics or genetic technologies in the last month?

	%	No.
Very interested	50%	269
Fairly interested	38%	203
Not very interested	8%	43
Not at all interested	3%	16
I don't know	1%	6
	Base:	537

11. Please rank the sources you think are most likely to provide trustworthy information and advice about genetic technologies. Your first click is the source you consider most trustworthy. [Note: respondents were not asked to rank up to five choices, they could move to the next question once they had ranked 1 source]

	Total		Ranking				
			1	2	3	4	5
	100%						
Businesses working or funding research on genetic technologies			19%	22%	20%	21%	18%
% of those who ranked businesses working or funding research on genetic technologies			16%	20%	19%	22%	19%
Base:	1751	No.	335	381	347	374	314
Government bodies/ policy makers			16%	19%	24%	24%	17%
% of those who ranked Government bodies/ policy makers			14%	18%	23%	24%	19%
Base:	1763	No.	282	343	417	415	306
Charities and campaigning organisations			11%	16%	23%	22%	28%
% of those who ranked charities & campaigning organisations			9%	15%	22%	22%	31%
Base:	1741	No.	188	277	395	386	495

Regulatory organisations			14%	31%	25%	21%	9%
% of those who ranked regulatory organisations			12%	29%	25%	22%	10%
Base:	1803	No.	245	559	454	383	162
University academics, scientists and researchers			49%	18%	11%	8%	15%
% of those who ranked university academics, scientists and researchers			43%	17%	11%	8%	17%
Base:	1818	No.	895	320	194	142	267
None of the above			45%	9%	9%	11%	27%
% of those who ranked none of the above			6%	1%	1%	2%	4%
	259	No.	116	22	22	29	70
	% of sample		100.00%	92%	89%	84%	78%
Base of those who ranked each column		No.	2061	1902	1829	1729	1614

12. (Humans) Use the following grid to give your view on the extent to which the developments listed below can be seen to be positive or negative for society:

		%	No.
Using genome sequencing in humans as a way of identifying the risk of life threatening diseases (e.g. breast cancer linked to mutations in the BRCA gene)	Very positive	51%	1058
	To some extent positive	33%	681
	To some extent negative	6%	116
	Very negative	2%	33
	I don't know	8%	173
	Base:		2061
Using genome editing in patients as a way of curing an otherwise incurable life threatening disease (e.g. muscular dystrophy)	Very positive	52%	1064
	To some extent positive	31%	639
	To some extent negative	7%	149
	Very negative	2%	43
	I don't know	8%	166
	Base:		2061
Using genome editing in patients as a way of curing an otherwise curable life threatening disease (e.g. leukemia)	Very positive	47%	969
	To some extent positive	35%	712
	To some extent negative	7%	153
	Very negative	3%	56
	I don't know	8%	171
	Base:		2061
Using genome editing to treat a non-life threatening disease (e.g. arthritis)	Very positive	31%	628
	To some extent positive	42%	867
	To some extent negative	12%	256
	Very negative	5%	106
	I don't know	10%	204

		Base:	2061
Using genome editing to correct a genetic disorder so that the correction would also be inherited by any children of that person (e.g in case of hypertrophic cardiomyopathy, which may result in heart failure)	Very positive	43%	893
	To some extent positive	33%	675
	To some extent negative	10%	202
	Very negative	4%	82
	I don't know	10%	209
		Base:	2061
Using genome editing to correct a genetic disorder in a way that would not be inherited by any children of that person	Very positive	32%	668
	To some extent positive	39%	806
	To some extent negative	13%	266
	Very negative	4%	89
	I don't know	11%	232
		Base:	2061

13. To what extent do you agree that genetic technologies such as genome sequencing and editing should be used in humans for prolonging life beyond current life expectancies?

	%	No.
Strongly agree	15%	308
Agree to some extent	39%	797
Disagree to some extent	22%	460
Strongly disagree	12%	245
I don't know	12%	251
	Base:	2061

	%	No.
Strongly agree	Base:	308
18-34 year olds	21%	131
35-54 year olds	14%	105
55+ year olds	10%	72
Agree to some extent	Base:	797
18-34 year olds	41%	259
35-54 year olds	40%	290
55+ year olds	35%	248
Disagree to some extent	Base:	460
18-34 year olds	20%	126
35-54 year olds	21%	152
55+ year olds	26%	182
Strongly disagree	Base:	245
18-34 year olds	8%	48
35-54 year olds	12%	87
55+ year olds	16%	110
I don't know	Base:	251
18-34 year olds	11%	71
35-54 year olds	13%	92
55+ year olds	13%	88

14. To what extent do you agree that genome editing should be used in humans for cosmetic reasons (e.g. changing a person's eye or hair colour)?

	%	No.
Strongly agree	7%	135
Agree to some extent	17%	345
Disagree to some extent	18%	379
Strongly disagree	50%	1036
I don't know	8%	166
	Base:	2061

	%	No.	Base:
Strongly agree	Base:	135	
18-34 year olds	13%	84	635
35-54 year olds	5%	39	726
55+ year olds	2%	12	700
Agree to some extent	Base:	345	
18-34 year olds	21%	132	635
35-54 year olds	17%	127	726
55+ year olds	12%	86	700
Disagree to some extent	Base:	379	
18-34 year olds	20%	124	635
35-54 year olds	17%	127	726
55+ year olds	18%	128	700
Strongly disagree	Base:	1036	
18-34 year olds	39%	246	635
35-54 year olds	51%	372	726
55+ year olds	60%	418	700
I don't know	Base:	166	
18-34 year olds	8%	49	635
35-54 year olds	8%	61	726
55+ year olds	8%	56	700

15. To what extent do you agree that genome editing should be used in humans to enhance abilities (e.g. changing a person's intelligence)?

	%	No.
Strongly agree	10%	207
Agree to some extent	22%	449
Disagree to some extent	25%	524
Strongly disagree	35%	710
I don't know	8%	171
	Base:	2061

16. Use the following grid to give your view on the extent to which the developments listed below can be seen to be positive or negative for society:

		%	No.
Using genome editing in animals as a way of preventing human disease (e.g. using genetically modified mosquitoes to limit the spread of malaria, dengue and zika), even if there may be an effect on the ecosystem	Very positive	33%	684
	To some extent positive	37%	772
	To some extent negative	13%	262
	Very negative	6%	117
	I don't know	11%	226
		Base:	2061
Using genome editing in animals as a way of preventing crop damage (e.g. using genetically modified moths to limit the growth in pest populations that feed on crops), even if there may be an effect on the ecosystem	Very positive	18%	380
	To some extent positive	38%	776
	To some extent negative	22%	454
	Very negative	9%	187
	I don't know	13%	264
		Base:	2061
Using genome editing in animals as a way of curing human disease (for example adapting pig organs so that they are suitable for use in human transplants)	Very positive	24%	495
	To some extent positive	37%	755
	To some extent negative	17%	351
	Very negative	9%	189
	I don't know	13%	271
		Base:	2061
Using genome editing in animals as a way of removing invasive species (e.g. the Asian hornet in the UK)	Very positive	23%	464
	To some extent positive	37%	759
	To some extent negative	18%	376
	Very negative	9%	184
	I don't know	13%	278
		Base:	2061

17. Use the following grid to give your view on the extent to which using genetic technologies in animals **for food** is a positive or negative development for society when this is done to:

		%	No.
Increase the efficiency of food production (e.g. genetically modified farmed salmon that require less food to reach a target weight)	Very positive	18%	378
	To some extent positive	33%	670
	To some extent negative	23%	470
	Very negative	14%	289
	I don't know	12%	254
		Base:	2061
Prevent disease (e.g. genome edited pigs that are resistant to African Swine Fever)	Very positive	28%	568
	To some extent positive	43%	879
	To some extent negative	15%	299
	Very negative	5%	93
	I don't know	11%	222
		Base:	2061

Improve animal welfare (e.g. genome edited cattle that do not have horns and so do not need to be dehorned)	Very positive	21%	423
	To some extent positive	32%	654
	To some extent negative	23%	466
	Very negative	11%	235
	I don't know	14%	283
		Base:	2061
Increases profitability (e.g. genome edited cattle that grow larger)	Very positive	11%	232
	To some extent positive	22%	461
	To some extent negative	29%	605
	Very negative	24%	499
	I don't know	13%	264
		Base:	2061

		%	No.	Base:
Increase the efficiency of food production (e.g. genetically modified farmed salmon that require less food to reach a target weight)	Very positive	Base:	378	
	18-34 year olds	28%	179	635
	35-54 year olds	13%	94	726
	55+ year olds	15%	104	700
	To some extent positive	Base:	670	
	18-34 year olds	33%	207	635
	35-54 year olds	29%	207	726
	55+ year olds	37%	256	700
	To some extent negative	Base:	470	
	18-34 year olds	18%	116	635
	35-54 year olds	28%	206	726
	55+ year olds	21%	149	700
	Very negative	Base:	289	
	18-34 year olds	11%	73	635
	35-54 year olds	15%	112	726
	55+ year olds	15%	103	700
	I don't know	Base:	254	
	18-34 year olds	9%	60	635
	35-54 year olds	15%	107	726
	55+ year olds	13%	88	700

		%	No.	Base:
Increases profitability (e.g. genome edited cattle that grow larger)	Very positive	Base:	232	
	18-34 year olds	18%	115	635
	35-54 year olds	10%	70	726
	55+ year olds	7%	47	700
	To some extent positive	Base:	461	
	18-34 year olds	25%	158	635
	35-54 year olds	19%	140	726
	55+ year olds	23%	163	700
	To some extent negative	Base:	605	
	18-34 year olds	24%	154	635
	35-54 year olds	32%	229	726
	55+ year olds	32%	221	700
	Very negative	Base:	499	
	18-34 year olds	21%	133	635
	35-54 year olds	25%	184	726
	55+ year olds	26%	181	700
	I don't know	Base:	264	
	18-34 year olds	12%	75	635
	35-54 year olds	14%	103	726
	55+ year olds	13%	88	700

18. To what extent do you agree that genome edited animals for food production should be subject to more rigorous testing and stricter regulations than conventionally bred animals to ensure the product is fit for human consumption?

	%	No.
Strongly agree	47%	962
Agree to some extent	29%	596
Disagree to some extent	10%	212
Strongly disagree	5%	98
I don't know	9%	193
	Base:	2061

19. To what extent do you agree that genome editing should be used in animals for cosmetic reasons (e.g. in pets such as fluorescent fish or micro-pigs)?

	%	No.
Strongly agree	7%	152
Agree to some extent	12%	255
Disagree to some extent	15%	301
Strongly disagree	57%	1184
I don't know	8%	169
	Base:	2061

20. To what extent do you consider it to be positive or negative for society to use genetic technologies in plants for the cost-effective development of medicines (e.g. using genome editing to modify tobacco plants to produce bio-pharmaceuticals)?

	%	No.
Very positive	27%	547
To some extent positive	43%	879
To some extent negative	9%	187
Very negative	5%	112
I don't know	16%	336
	Base:	2061

21. Use the following grid to give your view on the extent to which it is positive or negative for society to use genetic technologies to produce plants **for food** when this is done to:

		%	No.
Make crops more compatible with chemical inputs (e.g. maize that is resistant to herbicides)	Very positive	22%	450
	To some extent positive	36%	735
	To some extent negative	19%	400
	Very negative	8%	166
	I don't know	15%	310
		Base:	2061
Make crops more nutritious as a way of making them more marketable (e.g. broccoli with higher anti-oxidant levels)	Very positive	22%	457
	To some extent positive	37%	762
	To some extent negative	20%	404
	Very negative	9%	190
	I don't know	12%	248
		Base:	2061

Make crops more nutritious as a way of supplementing poor diets (e.g. Golden Rice that provides more dietary Vitamin A)	Very positive	31%	634
	To some extent positive	39%	806
	To some extent negative	14%	290
	Very negative	6%	115
	I don't know	10%	216
		Base:	2061
Prevent crop damage (e.g. preventing fungal disease in rice, wheat, maize, potatoes and soybeans)	Very positive	36%	739
	To some extent positive	41%	853
	To some extent negative	11%	223
	Very negative	3%	63
	I don't know	9%	183
		Base:	2061
Reduce the environmental impact of agriculture (e.g. wheat that can use nitrogen from the air, reducing the need for adding nitrogen in the form of fertilisers)	Very positive	33%	683
	To some extent positive	38%	781
	To some extent negative	12%	238
	Very negative	5%	108
	I don't know	12%	251
		Base:	2061

		%	No.	Base:
Make crops more nutritious as a way of making them more marketable (e.g. broccoli with higher anti-oxidant levels)	Very positive	Base:	457	
	18-34 year olds	27%	172	635
	35-54 year olds	19%	136	726
	55+ year olds	21%	149	700
	To some extent positive	Base:	762	
	18-34 year olds	36%	231	635
	35-54 year olds	36%	263	726
	55+ year olds	38%	268	700
	To some extent negative	Base:	404	
	18-34 year olds	18%	114	635
	35-54 year olds	22%	160	726
	55+ year olds	19%	130	700
	Very negative	Base:	190	
	18-34 year olds	9%	58	635

	35-54 year olds	9%	67	726
	55+ year olds	9%	65	700
	I don't know	Base:	248	
	18-34 year olds	10%	61	635
	35-54 year olds	14%	100	726
	55+ year olds	12%	87	700

22. To what extent do you agree that genome edited plants for food production should be subject to more rigorous testing and stricter regulations than conventionally bred plants to ensure the product is fit for human consumption?

	%	No.
Strongly agree	47%	974
Agree to some extent	33%	688
Disagree to some extent	8%	165
Strongly disagree	2%	47
I don't know	9%	187
	Base:	2061

23. To what extent do you agree that genome edited plants should be cultivated in such a way as to prevent cross-contamination with related plants that have not undergone genome editing?

	%	No.
Strongly agree	42%	865
Agree to some extent	30%	628
Disagree to some extent	10%	212
Strongly disagree	4%	77
I don't know	14%	279
	Base:	2061

24. To what extent do you agree that regulation should focus on the outcome (e.g. herbicide resistant crops) rather than the method used to deliver that outcome (e.g. conventional breeding, genetic modification or genome editing)?

	%	No.
Strongly agree	18%	378
Agree to some extent	39%	795
Disagree to some extent	16%	323
Strongly disagree	7%	149
I don't know	20%	416
	Base:	2061

25. To what extent do you agree that genome editing and genetic modification should be used in plants for cosmetic reasons (e.g. to make vegetables look more attractive to the consumer)?

	%	No.
Strongly agree	8%	155
Agree to some extent	15%	310
Disagree to some extent	17%	359
Strongly disagree	51%	1045
I don't know	9%	192
	Base:	2061

26. Use the following grid to click on the position that best reflects your views for each of the following statements:

		%	No.
Genome editing opens new opportunities to tackle global challenges	Strongly agree	34%	703
	Agree to some extent	45%	930
	Disagree to some extent	7%	153
	Strongly disagree	2%	48
	I don't know	11%	227
		Base:	2061
Genome editing carries too many risks to be used to tackle global challenges	Strongly agree	15%	318
	Agree to some extent	30%	624
	Disagree to some extent	31%	629
	Strongly disagree	8%	159
	I don't know	16%	331
		Base:	2061
The use of genome editing to tackle global challenges is morally wrong	Strongly agree	11%	236
	Agree to some extent	23%	464
	Disagree to some extent	34%	701
	Strongly disagree	16%	330
	I don't know	16%	330
		Base:	2061
The use of genome editing must be balanced with other ways of tackling global challenges	Strongly agree	36%	733
	Agree to some extent	43%	881
	Disagree to some extent	8%	170
	Strongly disagree	3%	59
	I don't know	11%	218
		Base:	2061

Research into genetic technologies in humans, animals, plants and microorganisms is conducted according to appropriate regulatory frameworks in the UK	Strongly agree	36%	735
	Agree to some extent	32%	663
	Disagree to some extent	10%	209
	Strongly disagree	2%	41
	I don't know	20%	412
		Base:	2061

		%	No.	Base:
Research into genetic technologies in humans, animals, plants and microorganisms is conducted according to appropriate regulatory frameworks in the UK	Strongly agree	Base:	735	
	18-34 year olds	29%	181	635
	35-54 year olds	34%	249	726
	55+ year olds	43%	305	700
	Agree to some extent	Base:	663	
	18-34 year olds	34%	216	635
	35-54 year olds	32%	232	726
	55+ year olds	31%	215	700
	Disagree to some extent	Base:	209	
	18-34 year olds	14%	88	635
	35-54 year olds	12%	85	726
	55+ year olds	5%	36	700
	Strongly disagree	Base:	41	
	18-34 year olds	2%	15	635
	35-54 year olds	2%	14	726
	55+ year olds	2%	12	700
	I don't know	Base:	412	
	18-34 year olds	21%	134	635
	35-54 year olds	20%	147	726
	55+ year olds	19%	131	700

27. Do you think there should be a global regulatory framework for genetic technologies?

	%	No.
All ages		
Yes	81%	1673
No	6%	129
I don't know	13%	259

	Base:	2061
18-34 year olds		
Yes	79%	503
No	8%	48
I don't know	13%	84
	Base:	635
35-54 year olds		
Yes	79%	570
No	7%	53
I don't know	14%	103
	Base:	726
55+ year olds		
Yes	86%	600
No	4%	28
I don't know	10%	72
	Base:	700

28. Genetic technologies should be used as one of the ways of addressing pressing global challenges if:

		%	No.
There is no alternative means of delivering the same outcome	Strongly agree	24%	486
	Agree to some extent	38%	786
	Disagree to some extent	15%	300
	Strongly disagree	5%	108
	I don't know	18%	381
		Base:	2061
They provide a lower cost option than existing alternatives	Strongly agree	18%	366
	Agree to some extent	41%	836
	Disagree to some extent	16%	339
	Strongly disagree	5%	108
	I don't know	20%	412
		Base:	2061
They provide a less environmentally harmful option than existing alternatives	Strongly agree	27%	564
	Agree to some extent	37%	770
	Disagree to some extent	14%	283
	Strongly disagree	4%	88
	I don't know	17%	356

		Base:	2061
They have fewer negative side effects than existing alternatives	Strongly agree	25%	511
	Agree to some extent	36%	732
	Disagree to some extent	16%	330
	Strongly disagree	5%	111
	I don't know	18%	377
		Base:	2061
They are subject to fewer intellectual property restrictions (e.g. patents) than existing alternatives	Strongly agree	14%	298
	Agree to some extent	32%	652
	Disagree to some extent	18%	370
	Strongly disagree	9%	176
	I don't know	27%	565
		Base:	2061
They provide a more profitable option than existing alternatives	Strongly agree	14%	293
	Agree to some extent	34%	690
	Disagree to some extent	19%	399
	Strongly disagree	11%	222
	I don't know	22%	457
		Base:	2061
Each use is subject to careful scrutiny and regulation	Strongly agree	41%	841
	Agree to some extent	30%	608
	Disagree to some extent	10%	214
	Strongly disagree	3%	65
	I don't know	16%	333
		Base:	2061

29. At birth you were described as?

	%	No.
Male	46%	946
Female	53%	1099
Other	0%	4
I prefer not to say	1%	12
	Base:	2061

30. How would you describe yourself now?

	%	No.
Male	46%	956
Female	53%	1085
Other	0%	9
I prefer not to say	1%	11
	Base:	2061

31. Which of the following best describes where you live?

	%	No.
Urban - city	28%	567
Urban - town	31%	634
Suburban	23%	469
Village	16%	339
Hamlet or isolated dwelling	3%	52
	Base:	2061

32. Which of the following comes closest to your personal working status?

	%	No.
Working full time (30 hours or more per week)	41%	840
Working part time (between 8 and 29 hours per week)	14%	295
Not working but on parental leave	1%	22
Not working but with full-time caring responsibilities	4%	86
Not working but seeking work and temporarily unemployed or sick	6%	128
Not working and not seeking work	7%	151
Student	7%	138
Retired on a state pension only	4%	89
Retired with a private pension	15%	312
	Base:	2061

33. Which of the following best describes your marital status?

	%	No.
Single	27%	548
Married	48%	987
Co-habiting	14%	281
Separated	2%	35
Divorced	7%	138
Widowed	2%	50
Prefer not to say	1%	22
	Base:	2061

34. Which of the following best describes your family status?

	%	No.
Pre-family	9%	195
Young family (children up to 10 years of age)	17%	357
Older family (children of 11+)	16%	333
Mix of younger & older children	6%	114
Empty nester (all children moved out)	24%	485
No children	28%	577
	Base:	2061

35. What is your religion?

	%	No.
Christian (Church of England, Church of Ireland, Church of Wales, Church of Scotland)	30%	625
Christian (All other protestant denominations)	9%	177
Christian (Roman Catholic)	11%	225
Buddhist	1%	30
Hindu	1%	30
Jewish	1%	11
Muslim	3%	56
Sikh	0%	6
No religion	39%	803
Prefer not to say	4%	76
Other, please specify	1%	22
	Base:	2061

36. Choose one option which best describes your ethnic group

	%	No.
English/ Welsh/ Scottish/ Northern Irish/ British	79%	1627
Irish	1%	23
Gypsy or Irish Traveller	0%	8
Any other White Background	7%	139
White & Black Caribbean	1%	13
White & Black African	1%	14
White & Asian	1%	28
Any other mixed/ multiple ethnic background	1%	16
Indian	2%	39
Pakistani	1%	18
Bangladeshi	0%	7
Chinese	1%	26
Any other Asian background	1%	15

African	1%	22
Caribbean	0%	9
Any other Black/ African/ Caribbean background	0%	4
Arab	1%	14
Prefer not to stay	2%	39
	Base:	2061

37. What is the highest educational level that you have achieved to date?

	%	No.
No formal education	1%	24
Primary school	1%	23
Secondary school, high school, NVQ levels 1-3	47%	972
University degree or equivalent professional qualification NVQ level 4	34%	700
High university degree, doctorate, MBA, NVQ level 5	15%	307
I don't know	0%	10
Prefer not to say	1%	25
	Base:	2061

38. Are you a member of a professional network or campaigning group?

	%	No.
Yes	9%	197
No	88%	1783
I don't know	3%	66
	Base:	2046

39. If yes, which?

	%	No.
38 degrees	2%	3
AAT	0.5%	1
ACCA	0.5%	1
AIIC	0.5%	1
BCS	0.5%	1
BPS - student member	0.5%	1
British Computer Society, Rethink Mental Illness	0.5%	1
British Psychological Society - student member.	0.5%	1
CCH	1%	2
Chartered Institute of Procurement & Supply	1%	2
cii/pfs	0.5%	1
cima	0.5%	1

CIPD	0.5%	1
EAPPI	0.5%	1
Environmental	0.5%	1
Greenpeace	1.5%	3
I am a member of a teaching union	0.5%	1
I am a member of both the Royal Aeronautical Society and the British Interplanetary Society.	0.5%	1
I am not a member of a prof network, or campaigning group but suffer from Menieres syndrome so would welcome genetic modification to get rid of this debilitating disease.	0.5%	1
I am secretary of a group which saved 50 acres of land from having 600 houses built on it and now look after this area for the use of the entire community, & I'm treasurer of Hertsmere Boroughwatch.	0.5%	1
I am very much in favour of these. They the only way we will get change as far as I'm concerned. Cheap to research and cheap to perform	0.5%	1
I sign various change.org & 38Degrees petitions	0.5%	1
IChemE	1%	2
IET	0.5%	1
if you mean Union - Yes Political party - Yes	0.5%	1
Institute of Mechanical Engineers (IMechE)	0.5%	1
Institute of Occuapational Health (IOSH)	0.5%	1
Labour party, royal society of biology	0.5%	1
Linked in, 38 degrees	0.5%	1
Linked-In	0.5%	1
Llnkedin	3%	6
LinkedIn; WaterAid; GreenPeace	0.5%	1
Local community improvement group	0.5%	1
NASUWT	0.5%	1
National Secular Society, Taxpayers Alliance	0.5%	1
PETA and Cats Protection also change.org and HSI global	0.5%	1
PhD student of botany specialization molecular genetics near to submission of dissertation	0.5%	1
Professional Institutions	0.5%	1

prospect, British ecological society, royal statistical society, society for mathematical biology	0.5%	1
RoCA	0.5%	1
royal biological society	0.5%	1
RSPB	0.5%	1
save the children	0.5%	1
Teachers	0.5%	1
The British Psychological Society	0.5%	1
the Methodist Church	0.5%	1
The Vegan Society	0.5%	1
Trade Union	1%	2
WASPI	0.5%	1
WHICH	0.5%	1
Your Able 38 degrees	0.5%	1
	Base:	64*

\*Not all those that answered 'yes' to question 38 responded with the name of an organisation to question 39.

40. Which of the following media outlets, if any, do you read regularly, either in print or digital format? By regularly we mean at least three times a week [Click on all the answers that apply to you].

	%	No.
Buzzfeed	11%	218
Daily Express/ Sunday Express	11%	230
Daily Mail/ Mail on Sunday	26%	543
Daily Mirror/ Sunday Mirror	11%	235
Daily Star/ Daily Star Sunday	4%	91
Daily Telegraph/ Sunday Telegraph	9%	189
Huffington Post	7%	141
Metro	15%	316
Paid for local paper	8%	168
The Guardian	15%	299
The Observer	4%	87
The Sun/ the Sun on Sunday	10%	197
The Times/ Sunday Times	11%	233
None of the above	32%	666
Other, please write in this box to tell us which	3%	68

41. Which of the following social media sites or apps, if any, do you use regularly? By regularly we mean at least three times a week [Click on all the answers that apply to you].

	%	No.
Facebook	66%	1365
Instagram	26%	539
LinkedIn	15%	312
My Space	4%	81
Pinterest	14%	298
Reddit	4%	79
Snapchat	13%	265
Tumblr	3%	72
Twitter	23%	472
YouTube	40%	815
None of the above	20%	406
Other, write in this box to tell us which	1%	12