



# **Should the UK consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions?**

**REPORT OF THE UK CITIZENS JURY ON HUMAN EMBRYO EDITING**

**13<sup>TH</sup>-16<sup>TH</sup> SEPTEMBER 2022**

The citizens jury deliberated over 4 days on the following question:  
“Are there any circumstances under which a UK Government should consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions?”

## IMPLEMENTATION PARTNERS

<b>Involve UK</b>	Lead facilitation, process design and reporting in the jury's recommendations
<b>Genetic Alliance UK</b>	Recruitment and organisational partner
<b>Wellcome Connecting Science and Involve UK</b>	Table facilitation
<b>Monster Films and Labada Films</b>	Filmmakers
<b>University of Canberra and KU Leuven</b>	Independent evaluators

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## EXECUTIVE SUMMARY

Scientists can now edit the code of life (the genome) with relative ease and precision. However, the idea of permanently changing the human genome in future generations generates strong opinions. In the UK, as in most countries worldwide, it is illegal to perform genome editing on embryos that lead to pregnancy.

Whilst the editing process is not currently 100% accurate, scientists predict that it soon will be. This means that public audiences should be brought into the conversation now about the application of the technology so that policy makers can take account of societal perspectives when discussing the legislation. Being able to change the DNA of human embryos has been hailed as a game changer for potentially curing some hereditary genetic disorders from all future generations in a family. However, for cultural, religious, or ethical reasons, some feel the manipulation of human embryos is a step too far for society.

Families with a known genetic disorder already have the option to use genetic testing to try and have children who are unaffected by the disease. But these technologies don't work for everyone.

## THE CITIZENS JURY

For a week in September 2022, 21 people with personal experience of genetic disease travelled from across the UK to the Wellcome Genome Campus near Cambridge to sit as members of the UK Citizens Jury on Genome Editing. The jury members were selected to broadly reflect the demographic make-up of patients who are eligible to use genomic medicine services and genetic counselling in the NHS.

A citizens jury typically involves a period of intense learning from experts, focused deliberations, voting on an ethical question and the writing of policy recommendations – and that is exactly what they did here.

The aim was to provide an insight into the perspectives of a group of patients with inherited genetic conditions on what they think about the benefits, risks and wider harms emerging from the application of embryo genome editing. Their recommendations support policy makers, researchers and wider civil society to better understand informed public perspectives.

The jurors welcomed the opportunity to have their voices heard and felt that public engagement on genome editing shouldn't be left to chance. The technology is developing fast and the jurors believed that some groups would start lobbying for a change in the law in the not-too-distant future.

They asked for policy makers to be proactive in shaping the inevitable debate which will begin and ensure that all voices within society are heard as it develops. Many of the jurors were clear that they did not want to stop scientific advancement but rather wanted it to be done in a transparent way that took account of their lived experience of having or being affected by a serious genetic disease. Changing the DNA of human embryos was re-framed by some of the jurors as a form of 'treatment' for genetic disease (and thus this term is used in the report).

The citizens jury deliberated over 4 days on the following question:

**Are there any circumstances under which a UK Government should consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions?**

When polled at the end of the process the majority of the jurors agreed (17 to 4) that the government should consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions, and most felt that these discussions should be beginning now.

The views that informed this conclusion were nuanced and complex and, whilst the majority expressed broad support for the clinical application of the technology, there were limitations and conditions attached to this. A minority also felt extremely concerned about the structural inequalities for disabled people that currently exist and thus could not contemplate supporting embryo editing at the present time.

## **OVERVIEW OF RECOMMENDATIONS**

The 15 recommendations that the jury made about the circumstances that needed to be in place before decisions are made to allow the intentional genome editing of human embryos are summarised below. They have been grouped into 4 themes, developed as part of our analysis of the jurors' deliberations after the event.

## **Theme 1: Develop an inclusive process for deciding whether to proceed with genome editing**

The jury believed that policy makers must work to ensure a diversity of voices across society are involved in any debate about changing the law. They argued strongly that this must include patients who self-identify as having a personal and/or family history of inherited disease and parents and carers of people with serious genetic conditions, alongside policy makers, scientists, clinicians and the wider public. Further, they emphasised that those with lived experience need to be supported and empowered to have genuine influence.

*As part of discussions about changing the law, there is a need to ...*

1. Develop a clear plan and timeline if discussions begin about changing the law so that the potential benefits of genome editing can be made available for future generations.
2. Ensure equity and diversity are central to all decisions about whether and how to proceed.
3. Avoid unintended consequences and the risk of further marginalising already marginalised groups.
4. Ensure ongoing engagement between decision makers and users of services.

## **Theme 2. Put in place effective support to ensure equitable access to treatment**

Jurors considered what support should be available to potential parents considering using the technology and to children born through the use of genome editing. A strong strand of the jury's deliberations related to the current unequal access to publicly funded health and social care services across the UK. Whilst providing access to assisted reproductive technologies for free via the NHS was deemed necessary, jurors argued that the current inequalities of access to services needed to be dealt with as part of any decision on whether or not to legalise embryo editing for heritable diseases.

*As part of discussions about changing the law, there is a need to ...*

5. Develop a clear framework for giving and obtaining consent so that a balanced decision can be taken in the best interests and respecting the rights of the embryo, child and parents.
6. Ensure genuine choice so that there is an option to say no to the technology and be in no way disadvantaged.

7. Provide fair and balanced evidence about genetic conditions so that people understand what it is like to live with the condition and have all the information they need to make an informed decision about editing.
8. Ensure support is available, i.e. support services are accessible to everyone and people's physical, emotional and mental health are safeguarded.
9. Provide transparent information, e.g. a hub where patients and families can have access to all information regarding embryo editing and a 'one-stop shop' for information on genomics.
10. Ensure equitable access to publicly funded services centring the value of everyone's right to treatment to try and have a child (regardless of age, ability, socio-economic status, or ethnicity).

### **Theme 3. Protect the rights equally of those who decide to proceed or not to proceed with treatment**

Jurors identified the potential for discrimination and stigma regarding whether the choice was made to accept treatment or not. They want to see protections against this.

While recognising the potential benefits of the technology, this theme also reflects the concerns of some jurors that living with a genetic condition could mean that their lives are perceived as less valuable. These jurors were keen to see an acknowledgement that genome editing cannot erase the structural inequalities in society.

Jurors proposed that embryo editing status should become a protected characteristic so that there is no detrimental impact of either having used or not using the technology. They also focused on protecting those who may choose not to accept this treatment to ensure that they and their children are not disadvantaged by this choice. As part of this proposal, they asked policy makers to consider: if having genome editing is defined as a protected characteristic, how many generations does this apply to and should this protected status be extended to cover all carriers of genetic conditions?

*As part of discussions about changing the law, there is a need to ...*

11. Ensure equal access to insurance and no discrimination on the basis of genetic information, i.e. if you are an 'edited person' you should be able to access the same insurance as other people who have not had editing.

12. Ensure embryo editing is available via publicly funded health services and obtain clarity about the purpose of the private sector with respect to the delivery of such services.
13. Keep personal information private, with due consideration to protecting a parent's right not to disclose if they have had embryo editing and a child's right to not declare this either.

#### **Theme 4. Develop an equitable process and framework to reduce the wider social inequalities and the potential for harm**

This theme reflects the ongoing difference in opinion about how to balance the potential benefits of embryo editing against the potential negative impacts of the technology. The jury were keen to avoid the technology being used inappropriately and were clear that it should not be used for enhancement purposes or personal gain.

They recognised that pre-implantation genetic diagnosis (PGD) is currently available, but that it is not suitable for everyone and, if no unaffected embryos are created, parents cannot achieve a pregnancy. They felt that the option of embryo editing should be available as an alternative to PGD, if all PGD options have been exhausted or are not possible.

The jury also discussed whether a 'slippery slope' or 'creep' had already occurred with the use of PGD. There were concerns that opening up a debate about the legislation on embryo editing may itself impact negatively on those already living with disability, or born with a disability, and risks worsening society's judgement about what it means to be disabled. To counter these concerns this final set of jury recommendations calls for significant restrictions on the number and types of genetic conditions which genome editing should be considered for.

*As part of discussions about changing the law, there is a need to ...*

14. Ensure genome editing is only available if there are no alternatives.
15. Create a clear framework to identify genetic conditions for which genome editing is acceptable.



## VALUES THAT UNDERPIN THE RECOMMENDATIONS

The Jurors also identified 9 values which underpinned their deliberations and the recommendations they agreed. These are presented in Box 1 below. The Jurors will expect to see policy makers use these values to shape the debate if it develops. Further, they will want to see these values represented in any decisions which are made about whether the law should change and how the technology should be used.

- |                                     |                                 |
|-------------------------------------|---------------------------------|
| • Fairness                          | • Choice                        |
| • Inclusivity and Diversity         | • Transparency across the board |
| • Lived experience / co-production  | • Do no harm                    |
| • Person centred not profit centred | • Remain open and accountable   |
| • Future proof the process          |                                 |

BOX 1: UNDERPINNING VALUES AGREED BY MEMBERS ON DAY 4

“ The jury has been a rollercoaster emotionally and mentally. It has been amazing to hear the personal stories of the others on the jury. I won't call myself a 'juror' but a member of the UK jury family. ”

“ There are not many positives about living with a rare disease, but the experience of the Citizens Jury has certainly been one of them. I am grateful to have had this unique opportunity to have my say on one of society's most complex and significant issues. ”

COMMENTS FROM JURORS AT THE END OF THE PROCESS

## BACKGROUND TO THE CITIZENS JURY

The UK Citizens Jury on Genome Editing was convened as part of the policy call around the world to bring public audiences into engagement and conversation around the application of the technology.

Scientists can now edit the code of life (the genome) with relative ease and precision. However, the idea of permanently changing the human genome in future generations creates strong opinions. In the UK, as in most countries worldwide, it is illegal to perform genome editing on embryos that lead to a pregnancy.

The technology has been hailed as a game changer for potentially curing some hereditary genetic disorders from all future generations in a family. Some believe these potential benefits outweigh ethical reservations against the technology.

Others consider that, in light of existing alternatives, the ethical risks of genome editing are not justified. Families with a known genetic disorder already have the option to use genetic testing to try and have children who are unaffected by the disease; for example, they may choose to have genetic testing in pregnancy with the option to end the pregnancy if a genetic condition is identified or they may choose to have genetic testing of an embryo and choose to implant an embryo that is unaffected. These existing technologies can help families without going to the lengths of altering the genome of future generations and whilst they are available currently on the NHS they do not work for everyone.

As the technology continues to develop, the debate about genome editing is here to stay. Pressure from interested groups could mean that governments might soon have to decide whether the technology should be opened up for use to cure inherited diseases. If this happens, it is important that the public has been given the opportunity to consider and deliberate these matters, so that their views can inform any government's decision.

For the purposes of the citizens jury, we assumed that at some future time point, genome editing technologies will be optimised to ensure complete accuracy in terms of targeting the intended DNA and making the intended corrections, without off-target effects, 100% of the time. We fully appreciate that in 2022, the accuracy of genome editing techniques is not fully assured, but we assume that this will change in the near future. We took this approach so that we could focus primarily on the ethical and societal issues raised. If an edit is made to the DNA of a human embryo to correct or treat a genetic condition, this

has the capacity to be inherited by all future generations of offspring descended from that person. Such an edit could be made for embryos created from eggs and sperm from people affected by a genetic condition or carrying a genetic condition (and thus who have the risk of having a child affected by a genetic condition). Therefore, we also made the assumption that in the UK, if embryo editing was offered to patients in the NHS it would sit within clinical services that are guided by the principles of genomic medicine, i.e., available to genetics patients and their relatives who are concerned about serious inherited disease. Situating the debate within this setting means that the discussion is focused on disease rather than enhancement. It also orientates the stakeholders as genetics patients as opposed to the broader public

## THE JURY MEMBERS

The jury membership was designed to broadly reflect the make-up of patients who are eligible to use genomic medicine services and genetic counselling in the NHS.

## THE RECRUITMENT PROCESS

Genetic Alliance UK promoted the opportunity to submit an expression of interest in participating in the Jury through their networks including on their website, via newsletters and social media channels. They asked member organisations to promote the opportunity in their communities too. To ensure a diverse cohort we specifically approached Jnetics, the UK Thalassaemia Society and the Sickle Cell Society directly to encourage the promotion of the jury to their communities. These groups were chosen for direct outreach because of the specific ethnic backgrounds of their networks and financial support was provided to cover their costs incurred.

Potential participants filled out a survey to register their interest in taking part in the jury. The survey collected demographic information and information about the genetic condition they were affected by. Recruitment was open for 5 weeks.

The total number of expressions of interest received was 101 and, after removing duplicates and ineligible people, 95 applicants remained for shortlisting. Once shortlisted participants were provided with more information about the jury and asked to consent to be contacted about the project.

## THE CRITERIA APPLIED TO SELECTING JURORS

In deciding how to select the jury members the following criteria were agreed upon by the organisers:

- **Gender** - The sample was skewed to females, as more women attend clinical genetics clinics and the jury was designed to reflect the people who seek genetic counselling or attend genomic medicine services. It was agreed to construct the membership as 75% female and 25% male.
- **Age** – The UK as a whole has more people who are not of reproductive age (children and older people), given decisions within genetic counselling are most likely to be taken by people of reproductive age the membership was skewed towards reproductive age (i.e. under the age of 44).
- **Deprivation** – Level of educational attainment was used as a proxy to reflect UK demographics regarding socio-economic status.
- **Ethnicity** – Recognising that engagement projects on genetics often miss out on hearing voices from minority ethnic groups the choice was made to over-sample participants who did not self-identify as white. The aim, therefore, was for the jury to be made up of 50% who self-identified as white and 50% from other ethnicities.
- **Preimplantation genetic diagnosis** – It was important to hear from participants who had direct experience of thinking through reproductive options in relation to inherited conditions. The jury therefore over-represented participants who had considered having PGD.

## RANDOM SELECTION PROCESS

Working from the list of eligible applicants the team began with the criteria with the most constrained pool of potential members and applied a random number generator to undertake the selection. The process worked as follows:

- Round 1: Filtered for only applicants who had considered having PGD and selected those identified by the first 12 numbers generated, this resulted in 11 women and 1 man being selected.
- Round 2: selected for gender and the first 5 men identified were selected. The shortlist now had 12 people identifying as white and 5 as another ethnicity.
- Round 3: selected for ethnicity. The first 7 individuals identified by the random number generator who self-identified as an ethnicity other than white were added to the shortlist. This generated a sample which over-represented people with Sickle Cell Disease and Thalassaemia, so four were randomly removed.
- Round 4: selected at random from disease categories not represented in the current sample, then balanced the sample based on the perceived severity of disease.

This resulted in the planned Jury membership of 24. Unfortunately, in the lead-up to the event 3 people had to withdraw due to illness (all three self-identified as being Black British and all had either Sickle Cell Disease or Beta Thalassemia). Although attempts were made to replace them with applicants from the reserve list with a similar demographic this was not possible due to availability at late notice. This left 21 jurors to take part.

## PROFILE OF THE JURY MEMBERSHIP

AGE	#
18-24	3
25-34	3
35-44	8
45-54	4
55-64	1
65+	2
ETHNICITY	
White British	13
Indian	2
Pakistani	2
Mixed backgrounds	2
African	1
Arab	1
EXPERIENCE OF A GENETIC CONDITION	
Have a genetic condition	7
Parent of someone with a genetic condition	9
First degree relative (other than parent) of someone with a genetic condition	5
HAD OR HAVE CONSIDERED HAVING PGD	
Yes	9
No	11
Not sure	1

TABLE 1: PROFILE OF JURY MEMBERS

The genetic conditions represented among the membership had a broad range of life expectancy; some conditions had a life expectancy of early childhood, early adulthood, middle age or normal life expectancy. The conditions broadly affected the following systems:

- Blood disorder

- Cancer risk
- Connective tissue disorder
- Developmental
- Eye condition
- Lysosomal Storage Disease
- Metabolic
- Neurological
- Neuromuscular disorders

The majority of the cohort selected were first-degree relatives of someone affected by a genetic condition, with 7 out of 21 directly affected. In considering the balance between relatives and directly affected people, it is important to consider that 72% of genetic conditions have their onset in childhood, and many genetic conditions limit the capacity of those directly affected to advocate for themselves. All jurors' travel, hotel, childcare, food and subsistence costs were covered plus they each received an honorarium of £800.

Asymptomatic carriers of genetic conditions were not clearly identified in the survey design which is a consideration for the future.

## OVERSIGHT AND OPERATION OF THE CITIZENS JURY

### OVERSIGHT

An Oversight Group was appointed to support the project team to ensure that the jury, its framing, the questions it asked, and the materials and experts involved in briefing the jurors were as unbiased as possible. The Oversight Group met twice in the run-up to the jury. They met a third time to ensure that this report accurately represents the jury's deliberations and presents a useful resource for policy makers and others interested in the debate about genome editing for serious genetic conditions.

Their terms of reference can be found in Appendix 1.

The members of the Oversight Group were:

- **Mark Bale** - Department for Health and Social Care/ Genomics England (until April 2022)
- **Cath Joynson** - Nuffield Council on Bioethics
- **Sarion Bowers** - Wellcome Sanger Institute
- **Nick Meade** - Genetic Alliance UK

The project was funded and commissioned by Wellcome Connecting Science and governance for the project was signed off by the GRL Board (GRL is Genome Research Limited, the legal entity responsible for Wellcome Connecting Science and Wellcome Sanger Institute, chaired by Professor Sir Mike Stratton). This citizens jury project is categorised as an engagement project (not a research project), and thus ethical oversight and governance were offered by GRL Board as opposed to a Research Ethics Committee.

## **INVOLVED ‘IN THE ROOM’**

The project was commissioned and led by Anna Middleton (Wellcome Connecting Science) and the Engagement and Society team from Wellcome Connecting Science. It was designed by Simon Burall (Involve), and recruitment was led by Sophie Peet (Genetic Alliance UK).

Ben Tomlin, Marion Mitchell and Emma Garlick from Wellcome Connecting Science led on the logistics and practical support for the jurors (organising travel assistance, honoraria payments, and tailoring specific access support, e.g. providing fridges in the bedrooms for medication, breastfeeding room for nursing mothers, bottle warmers, baby baths, cushions for back support). Conor McCafferty (Involve) completed the onboarding of jurors (explaining what to expect and taking consent for filming) and this process was conducted over several weeks so that jurors had time to read the participant information and consent form about the project and make an informed decision about whether to participate. They also were given the option to talk to Ben Tomlin about the filming process.

As well as leading the project Anna Middleton provided independent and confidential support to jurors as needed in her role as a UK registered genetic counsellor. Sasha Henriques, an Expert Lead for the duration of the jury, also provided genetic counsellor support. Felicity Boardman was the second Expert Lead and was present for the first two days of the jury.

Lead Facilitators during the week were Simon Burall and Kaela Scott (Involve), who also designed the deliberative process and facilitated the jury to reach its conclusions. Table Facilitators were Damian Hebron and Alessia Costa from Wellcome Connecting Science, and Kathryn McCabe, a freelancer supplied by Involve.

The UK Citizens Jury on Genome Editing was also a creative project. Green Eyed Monster and Lambda Films were commissioned by Wellcome Connecting Science to film the

process and produce a short documentary. A crew of six plus the sound engineer filmed the daily jury sessions, interviewed members of the team, and undertook ‘vox pop’ interviews with jurors in a ‘diary room’. The ‘diary room’ was located in a space away from the main jury room and a space designed to hear from jurors about their experience of the jury, share how they were feeling about the process and their role in it, and whether they believed there was broader value of citizens’ juries as a tool of democratic participation.

Finally, to understand how well the process met deliberative standards, expert academics were invited to observe and evaluate. These evaluators also reviewed and assessed daily feedback from the jurors, allowing the process to be reiterated as necessary through the week, and providing learning for future events. The evaluation team at the UK Citizens Jury for Genome Editing were Nicole Curato and Lucy J. Parry from the University of Canberra and Lisa van Dijk from KU Leuven. An executive summary of their independent evaluation can be found in Appendix 2.

A number of observers from Wellcome Connecting Science and the Oversight Group were also present for some of the days.

## EVIDENCE AND INFORMATION

Citizens’ Juries are provided with evidence and information from experts and witnesses. The UK Citizens Jury on Genome Editing heard from 2 Expert Leads and ten expert witnesses. These contributions took place across the first 2 days of the jury, with days 3 and 4 focused on jurors’ deliberations.

Expert Witnesses	Title of presentation
Day 1	
<b>Sasha Henriques</b> , Doctoral student Wellcome Connecting Science and Principal Genetic Counsellor, Guy’s and St Thomas’s NHS Foundation Trust.	The science of heritable diseases
<b>Oliver Bower</b> , PhD student in the Human Embryo and Stem cell	Basic introduction to DNA, genes and germline editing



Laboratory at the Francis Crick Institute.	
<b>Sarah Norcross</b> , Director of Progress Educational Trust.	Presented twice on day 1: 1. The legal and policy context 2. Sort out the practicalities first – a pragmatic overview of the regulatory landscape and the role of the Human Fertilisation and Embryology Authority
<b>Dr Mark Sheehan</b> , Associate Professor and Oxford Biomedical Research Centre Ethics Fellow and the Ethox Centre in the Nuffield Department of Population Health.	Presented twice on day 1: 1. Application in a research setting (He Jiankui case) 2. What are we waiting for? Arguments from a bioethics perspective to embrace embryo editing
<b>Dr Sarah Bowdin</b> , Medical director of the East Genomic Laboratory Hub.	Potential application in a clinical setting
<b>Professor Felicity Boardman</b> , University of Warwick.	The ethical and social context and how serious genetic disease is discussed
<b>Professor Jackie Leach Scully</b> , Professor of Bioethics and Director of the Disability Innovation Institute, University of New South Wales, Australia.	We should wait (Video presentation), arguments from a bioethics perspective as to why we should not pursue embryo editing
Day 2	
<b>Dr Sarah Bowdin</b> , Medical director of the East Genomic Laboratory Hub.	A clinical perspective on the realism of genome editing
<b>Sara Levene</b> , Consultant Genetic Counsellor at the Centre for reproductive and Genetic Health.	A view from the private sector on pre-implantation genetic diagnosis, PGD services (Video presentation)
<b>Esther Fox</b> , Head of Accentuate.	Thoughts on what a personal ‘patient’ perspective is to live with a ‘serious genetic condition’ and the perceived threat of genome editing (Video presentation)

<b>Professor Trevor Stammers</b> , former Associate Professor of Bioethics and Medical Law and Director of the Centre for Bioethics and Emerging Technologies.	A Christian perspective
<b>Mufti Mohammed Zubair Butt</b> , Senior Advisor on Islamic law at the Institute of Islamic Jurisprudence, Bradford and Lecturer in Ethics of Organ Transplantation at the Markfield Institute of Higher Education	An Islamic perspective (Video presentation)
<b>Oliver Bower</b> , PhD student in the Human Embryo and Stem cell Laboratory at the Francis Crick Institute.	A research scientist’s perspective on the 14 day rule used in embryo research
<b>Dr Mark Bale</b> , former policy advisor and Programme Director for the 100,000 Genomes.	Policy context and perspective

TABLE 2: EXPERT SPEAKERS AND TOPICS

## OVERVIEW OF THE JURY PROCESS

The jury was held at the Wellcome Genome Campus near Cambridge. It took place over 4 days, from Tuesday to Friday, with jurors provided with onsite accommodation and catering. Prior to the jury convening, jurors were sent a handbook with some background information about genome editing including FAQs and a glossary. Hard copies of this handbook were also provided at the venue.

The first 2 days of the jury were focused on learning from expert presenters and developing dialogue between jurors about the information they were hearing and their reaction to it. Days 3 and 4 were focused on deliberation to develop recommendations and reach conclusions about the Jury question:

**Are there any circumstances under which a UK Government should consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions?**

This section describes in detail what happened on each of the 4 days citizens jury met, drawing out the key elements of jurors' deliberations (in blue text) and summarising the key outputs from each day.

## WELCOME AND ARRIVAL

The majority of the jurors gathered at the Wellcome Genome Campus Conference Centre on the evening before the jury started. They were given the opportunity to meet the other jurors present and the wider team. Over dinner, they were also invited to start to develop a set of conversation guidelines designed to set out how members wanted to work together and support each other throughout the process.

## DAY 1

The goal of the first two days of the jury was to develop the jurors' understanding of the issues associated with considering allowing intentional genome editing of human embryos for serious genetic conditions. While the members had been recruited because of their own lived experience of having a genetic condition or being directly related to someone with a condition, and therefore likely to have more understanding of the topic than the general public, given their diversity of experiences there was no reason to assume that jurors were all informed about the realities, complexities and possibilities of genome editing. Day 1 therefore focussed on ensuring a common, baseline understanding of the topic.

To support this there were 3 evidence sessions presented throughout the day, interspersed with time spent in facilitated discussions in small groups to begin identifying questions, concerns and key issues that they wanted to focus on. These focus areas were consolidated throughout the day to begin to 'map' the topics that the jury would consider when making recommendations.

## THE DELIBERATIVE PROCESS

After being introduced to the facilitation team, and given an outline of what to expect over the subsequent days, the jurors spent time in 3 small table discussions getting to know each other and sharing their motivations for joining the jury. Many had applied without expectation of being selected and were enthusiastic that they had been chosen. At this point many jurors also shared their personal experiences of either having a genetic/inherited condition or being directly related to someone who has. Several also

expressed feeling a sense of responsibility for representing the wider community of those impacted by genetic conditions.

Early in the day the jurors were also given back the conversation guidelines they had drafted the evening before. They added to these and agreed them as their 'rules for engagement' with each other over the 4 days. They can be seen in Box 2 below.

- Be open minded to different views
- Take turns listening and speaking
- Step-up, step-back
- Don't interrupt
- Pay attention and check you've understood
- Allow time to reflect and digest
- What is said in the room, stays here
- Disagree with ideas not people and don't get defensive
- All ideas have value
- Don't raise your voice
- Recognise that everyone is affected by an inherited condition
- Be respectful
- Keep the humour

BOX 2: CONVERSATION GUIDELINES AGREED BY MEMBERS ON DAY 1

In the first evidence session, designed to ensure a baseline understanding of heritable human genome editing, Sasha Henriques spoke about the science of heritable diseases, Oliver Bower gave a basic introduction to DNA, genes and genome editing and Sarah Norcross summarised the legal, regulatory and policy context to embryo research and assisted reproductive technologies in a clinical setting, including the use of pre-implantation genetic diagnosis and regulation of licences by the Human Fertilisation and Embryology Authority. After each short presentation jurors were given time at their tables to generate questions for the speakers that would help them answer the question the jury had been asked. The speakers then circulated to each of the three tables in turn answering the questions the jurors had prioritised.

The second evidence session allowed jurors to hear about potential applications of genome editing in different settings. Mark Sheehan spoke about the research setting,

sharing the story of the He Jiankui case<sup>1</sup> and discussing the bioethical debates around curing genetic disease. Sarah Bowdin spoke about the potential use in a clinical setting in the current NHS, and Felicity Boardman introduced some of the ethical and social context surrounding the debate, including different perceptions of disability. Again, jurors were given time after each presentation to discuss possible questions for the speakers which were answered in a plenary Q&A.

In the questions raised by jurors the concept of identity and how much a genomic condition or gene editing can impact on personality was prominent. In discussions, jurors with direct experience of a rare genetic condition were noticeably keen to share their experience of living with that condition, but also their wider reflections, for instance, that there are also benefits to having some genetic condition (sickle cell carriers have protection against malaria, for example). A few were also interested in the evolution of genetic conditions and what might be missed out on if that evolutionary path were altered. They noted the challenge of finding a balance between treating people with existing conditions and exploring gene editing for future humans, and how many people might ultimately be impacted. Some jurors were also concerned about the implications of research into a genetic disease to treat it while there was still limited understanding of why the disease occurs.

After lunch, jurors were introduced to the concept of the collective ‘map of issues to explore’ that they would be building throughout the process. To begin this process jurors were invited to think about what they had heard from the experts and think about what they identified as possible benefits, risks and uncertainties about the potential for genome editing for treating heritable disease. Jurors used post it notes to capture their responses to these prompts, and these were shared in the plenary and grouped to start a large visual ‘mind-map’ at the front of the room. At this stage some of the key themes that would be returned to throughout the week began to emerge.

Jurors explored how decisions are made around [eligibility and access to genomic treatments](#), something that raised ethical as well as practical questions for many of them. The [risk of genome editing becoming a ‘slippery slope’](#) was also raised. Some jurors also expressed [scepticism about ensuring genome editing was only used for](#)

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<sup>1</sup> In 2018, the world learned that He Jiankui had implanted embryos in which he had used CRISPR–Cas9 to edit a gene known as CCR5, which encodes an HIV co-receptor, with the goal of making them resistant to the virus. The implantation led to the birth of twins in 2018, and a third child was later born to separate parents. The parents had agreed to the treatment because the fathers were HIV-positive and the mothers were HIV-negative, and the couples were barred from access to alternative assisted-reproduction technologies in China. In December 2019, He was sentenced to three years in prison.

'good' and the ability of the NHS to meet demand equitably. Questions about risks, safety and unintended consequences also started to surface.

🗨️ *How can you be so certain?* 🗨️

ONE JUROR RESPONSE TO EXPERT PRESENTATIONS

Regulation and the need for scientists and researchers to act ethically, but at the same time for patients not to be disadvantaged because of the possible controversial aspects of genome editing, was also explored, particularly in response to Mark Sheehan's presentation about the He Jiankui case.

The theme of **ableism**, which would become a key focus as the week developed, was explored in response to Felicity Boardman's presentation which many jurors found both interesting and emotional. These discussions involved jurors beginning to think more about how genetic conditions have evolved, and unpicked words like 'correction' and 'enhancement'.

The final evidence session for day 1 continued to open up and problematise the pros and cons of genome editing and present different perspectives on whether a change in the law should be considered at this time. In his second presentation, Mark Sheehan spoke about the ethical imperative to act now in order to best be able to relieve suffering and cure disease. Jackie Leach Scully suggested that eradicating the impact of disease in this way is problematic and does not protect disability rights. She argued that we should rather work to understand and address the fact that society does not readily accommodate disability and the adverse effect that this has for some people with genetic conditions. Sarah Norcross asked jurors to think about whether genome editing for heritable conditions is even practically possible. She spoke about the resource and funding implications of prioritising this technology and explained more about pre-implantation genetic diagnosis and its use within assisted reproductive technologies, recognising that in reality the success rate is low (i.e. for each pregnancy cycle the viability of successfully implanting an unaffected embryo, that leads to the birth of a liveborn child, is low). She also highlighted that current PGD services are provided by both public and private healthcare systems, something that some might argue means access to care is inequitable. As with previous evidence sessions, jurors were given time to discuss and prioritise questions for the speakers. The speakers then circulated to each table to engage with the jurors' questions.<sup>2</sup>

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<sup>2</sup> Felicity Boardman, one of the expert leads, responded to questions posed by jurors about Jackie Leach Scully's presentation as this had been pre-recorded.

In their discussions about the evidence, jurors explored [the value of lived experience](#) and [the balance between correction, treatment or living with a condition](#). They were keen that decisions made in relation to genome editing took account of the multiplicity of ways that living with a genetic condition can impact a person – and that this can change as life progresses.

The question of who decides which conditions are treatable was raised, and jurors began to explore [what they felt defined ‘serious’ in relation to different conditions](#).

☞ *When I was diagnosed when I was 16, if you'd have interviewed me then and asked on whether I would have wanted to have (the genetic condition) or have someone take it away, it would have been very different to today. Because of course I was so angry and felt that nobody could understand how this felt and I had no idea about what my life would be like and what the impact would be. So definitely I would have said no, I don't want it. Yes, I don't. You know, I don't want any of this. But today I'm nearly 50. I have a really happy positive life. And I know that a huge part of that is because I have (the genetic condition) and there's no way I'd remove it. No way. But ask me that when I'm a week away from my next surgery that again could be different. I don't know that today. That could be different all over again.* ☞

A JUROR'S STATEMENT AT THE END OF DAY 1.

Jurors discussed [the concept of suffering](#) and the argument that there is an ethical imperative to reduce suffering if we can. They considered that suffering extends to friends and family as well as to the individual and cannot ever be wholly eradicated. Some wondered if the alleviation of all suffering would change societal structures - reflecting that [the world is not currently designed equitably for people with disabilities](#). They asked what the repercussions could be for people with disabilities if some conditions were edited out.

Several jurors were interested in how a line could ever be drawn between the value of genetic enhancements and therapeutic treatment, given that suffering is contextual. Jurors were anxious that, regardless of the outcome of genome editing, there should be [support available](#) for the child to understand what had happened and to deal with any [unforeseen consequences](#).

When considering investing more in genomic research, some jurors were concerned that directing research to genome editing might reduce the funding and research into treating and curing rare genetic disease (e.g. somatic therapies). They discussed concerns around [financial accessibility](#) and [genomic tourism](#). They wondered [how heritable genome editing intersected with IVF and PGD treatment](#). Choice started to become part of the discussion, with jurors wondering what the ‘offer’ might be to those who were genetic carriers of conditions.

The final exercise of Day 1 allowed jurors to work at their tables with a mini version of the map they had started to develop. Each table had a template flip chart with the cluster titles in each area of ‘exciting’, ‘uncertain’ and ‘concerning’. They had the opportunity to propose new ideas to add to the clusters or add new topics for consideration.

During these discussions, jurors noted that parents of those with genetic conditions or asymptomatic carriers had different priorities and concerns than those living with the impact of genetic conditions. This was a theme that played out for the remaining deliberations and impacted how jurors individually approached the questions posed to the jury.

The context of ‘society outside’ was a strong factor in many jurors’ own reflections and conversations. They were concerned that the conversation they were having was something that might not translate to, or resonate, within the wider world. [Pressures on the NHS, inequity, structural racism, and the fact that society is built to an ableist model](#) featured across the day.

After dinner on Day 1, jurors were invited to attend a screening of the Netflix film ‘Human Nature’. This documentary explains the science behind genome editing. It focuses on some of the motivations of the scientists working with the technology, and on the implications both from the perspectives of patients and ethicists. This was an optional social activity, but one that many jurors chose to attend.

## SUMMARY OF KEY OUTPUTS

By the end of Day 1, jurors had begun to develop a ‘mind-map’ of issues that were emerging from the presentations they had heard and their discussions about the implications of considering human embryo editing in a clinical setting. This map, combining the post-it notes capturing key points across each of the table discussions throughout the day grouped together with thematic headings, was created on a display



wall at the front of the room. It acted as a visual record of the jurors’ priorities and a tool the Jury would build on over the 4 days to prioritise areas of focus and develop and their recommendations.

What excites or concerns you, and where do you have uncertainties, around the potential for genome editing for treating heritable diseases?		
Excites	Uncertainties	Concerns
<ul style="list-style-type: none"> <li>• Enables families to make informed choices</li> <li>• Reduced pressure on NHS</li> <li>• Progress of science making this possible</li> <li>• Reducing suffering</li> <li>• Potential to target treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Access to all</li> <li>• Somatic vs germline editing (is germline needed if somatic is available?)</li> <li>• Would it make a difference?</li> </ul>	<ul style="list-style-type: none"> <li>• Who gives consent? (Parent or Child)</li> <li>• Risks i.e. eugenics / slippery slope</li> <li>• Long-term consequences / safety</li> <li>• Lack of trust in decision makers</li> <li>• External / societal judgement of choices</li> <li>• Social diversity and equity</li> <li>• International discrepancies / tensions</li> </ul>

TABLE 3: SUMMARY OF KEY ISSUES MAPPED BY JURORS AT THE END OF DAY 1

## DAY 2

The second day of the jury was designed to continue the jurors’ learning journey and introduce new and different perspectives on the issue that members may not yet have considered. Throughout the day, as well as hearing these presentations, the jurors spent time adding to and reworking their mind-map.

## THE DELIBERATIVE PROCESS

Day 2 began with Expert Leads Anna Middleton and Sasha Henriques reflecting on the previous day. Jurors were seated in new groups at each table so time in the morning was also dedicated to them getting to know the people they would be working with that day and reflecting on the process so far.

The first evidence session introduced professional and personal perspectives on the reality of genome editing in different scenarios. Sarah Bowdin offered her personal views on the current reality of genomic medicine services in the UK and whether a clinical application of germline editing would ever be possible. Sara Levene introduced jurors to the role of the private sector, what it offers that the NHS cannot and the potential market for embryo editing, including overseas. She also explained that PGD offers patients the ability to choose to implant an unaffected embryo (after it has had pre-implantation genetic testing to determine if the gene fault of interest is present or not) - this means that if there are no unaffected embryos, then there is no chance to implant a healthy embryo. If editing of human embryos is possible then this would provide a chance to correct the DNA of an affected early embryo, thus in theory presenting an increased chance of having a healthy embryo to implant. Esther Fox offered a patient perspective, arguing that genome editing threatens the identity of people with disabilities, especially when defining what constitutes a 'serious genetic condition' can be so subjective.

As on Day 1, jurors were given the chance to reflect after each presentation and consider what questions had arisen from what they had heard. The speakers responded to the questions in a plenary Q&A. As both Sara Levene and Esther Fox's contributions were pre-recorded videos, the expert leads, Sasha Henriques and Felicity Boardman contributed alongside Sarah Bowdin for this session.

Jurors then spent some time at their tables considering how what they had heard resulting in changes, additions or connections being made on their 'mini maps'. As jurors considered the reality of whether germline editing could ever move from research to a clinical application, they were prompted to consider the trade-offs between different treatments - and specifically the [trade-offs between genome editing of embryos and somatic gene therapy for patients](#). This reintroduced the issue of [consent - as somatic treatment allows consent to be given by the recipient, unlike germline editing \(the embryo cannot consent\)](#). The complexities of the trade-offs and the cost implications also led some jurors to again wonder [if focusing on genetic issues in the existing population should be the priority](#).

As jurors were introduced to a view from the private sector, the subtleties of [what 'equal access' actually means](#) were discussed. Jurors felt that, whether or not genome editing was allowed in the UK, those with adequate financial resources would seek treatment elsewhere and that [this 'genomic tourism' risked both deepening inequality and reducing the potential for research in the UK](#). Jurors also acknowledged that resource poverty was an international equity issue as well as one within the UK. Some saw [risks in an international race to be first with new genomic technologies](#). As a result, they asked if

international governance of genome editing was necessary. However, the jurors did not prioritise this in the recommendations.

They recognised that there needs to be NHS provision to avoid only the wealthy being able to access genome editing but acknowledged that NHS availability will not necessarily lead to equitable access. They asked how their recommendations might be imposed if institutions like the NHS are currently failing. The fear and despair around institutional failings, specifically the NHS and societal equity more broadly, led to jurors questioning how they could recommend change. Some became very concerned about the impact their recommendations could really have.

They began considering how private access might co-exist with NHS provision. Again, the question of 'who decides' was raised, as jurors considered what counts as therapy and what is considered enhancement. Jurors considered the perspective of someone living with a genetic condition for whom genome editing presents a challenge to their identity and how others perceive them. This prompted jurors to think philosophically about possible futures, unheard voices in the debate, including children, and choice.

In considering the future, some jurors wondered if reducing infant mortality by removing severe heritable conditions through genome editing might unwittingly make society more uncomfortable with child death. They wondered if, as rare conditions became rarer, would this limit support and research for those who were still impacted. If extreme conditions become less serious, what replaces them in the hierarchy? Relatedly, they discussed how to weigh up the seriousness of 'life threatening' or 'life limiting' as criteria for deciding whether genome editing should be legal or not.

☞ *Once extreme is 'edited out' the less extreme becomes extreme; where do we stop?* ☞

ONE JUROR'S RESPONSE TO THE PRESENTATIONS.

In considering choice and consent, while jurors acknowledged that people may value the lives they live with a genetic condition, others should be able to make their own decisions. However, they appreciated the difficulty inherent in genome editing essentially being a decision made by, usually a parent, on behalf of a child.

☞ *How do we decide for others? Children could disagree with parents' decision either way.* ☞

ONE JUROR'S RESPONSE TO THE PRESENTATIONS.

Before lunch, jurors heard from three speakers who offered their personal perspectives on the impacts of genome editing. Jurors heard a Christian perspective from Trevor Stammers, an Islamic perspective from Mufti Mohammed Zubair Butt, and Oliver Bower gave the perspective from his point of view as a research scientist. The idea of this session was to introduce some perspectives that this group of jurors might not necessarily have brought to the discussion. The religious perspectives focused on whether faith and a God precludes or supports embryo editing. Oliver chose to examine the more specific issue of the '14 day rule' which only allows embryos to be used in research from 0-14 days and what the benefits of extending this might be. All three presentations focused on who decides what can be done with embryos and when, and philosophical and scientific positions on when life is thought to begin.

As previously, jurors were given time after each speaker to consider questions they might ask, and after lunch, the three speakers joined each table to respond. On this occasion, Mufti Mohammed Zubair Butt had pre-recorded his contribution, so as expert lead, Sasha Henriques took a role to reflect with jurors about their questions related to his presentation.

These presentations sparked a vibrant conversation around religion between jurors. Overall they were respectful of belief systems but in general, felt that **ethics was a more universally applicable measure** and that **those with religious beliefs should not impose these on others** or expect science to comply with them.

🗨️ *Religion should not have a say in science.* 🗨️

ONE JUROR'S RESPONSE TO THE PRESENTATIONS.

The conversation around the limits placed on research on embryos by the 14-day rule reinforced jurors' views on **the necessity of those with lived experience being part of the decision making process about whether to extend this date to enable more research on human embryos**. This was further strengthened when jurors heard about how policy is developed, and decisions made in Whitehall in the final presentation.

The final evidence input came from Mark Bale. As someone with over 30 years' experience, he talked about government policy development in healthcare, and particularly the intersection between healthcare, research, ethics and legislation. Mark introduced jurors to the complexities of the policy making process. He reflected on what he thought the Department of Health and Social Care might want to know from the

citizens jury, and how they might, or might not, be able to act on this. He also gave some background to the global and European contexts. His talk was followed by a plenary Q&A.

## SUMMARY OF KEY OUTPUTS

After hearing the last of the evidence Jurors returned to considering the map of issues and areas of focus they had been developing over the 2 days at their tables. The lead facilitators then led a plenary session to consolidate the priorities identified by each group onto the collective map at the front of the room. The jurors were invited to discuss what they had added, changed, moved or removed from their mini maps and engage with the topics raised by other groups. Broad consensus from the whole of the jury was sought for any proposed movements, clustering, or removals from the map.

What excites or concerns you, and where do you have uncertainties, around the potential for genome editing for treating heritable diseases?		
Excites	Uncertainties	Concerns
<ul style="list-style-type: none"> <li>• Enables families to make informed choices</li> <li>• Reduced pressure on NHS</li> <li>• Progress of science making this possible</li> <li>• Reducing suffering</li> <li>• Potential to target treatment</li> <li>• Need for balanced evidence</li> </ul>	<ul style="list-style-type: none"> <li>• Somatic vs germline editing</li> <li>• Would it make a difference?</li> <li>• How to identify new conditions?</li> <li>• Consent</li> <li>• Privacy</li> <li>• What does it add?</li> <li>• Structural discrimination</li> </ul>	<ul style="list-style-type: none"> <li>• Who gives consent? (Parent or Child)</li> <li>• Risks, i.e. eugenics / slippery slope</li> <li>• Long-term consequences / safety</li> <li>• Lack of trust in decision makers</li> <li>• External / societal judgement of choices</li> <li>• Social diversity and equity</li> <li>• International discrepancies / tensions</li> <li>• Access to all</li> <li>• Hierarchies of conditions</li> <li>• Defining ‘serious’</li> <li>• Ethics of research</li> </ul>

TABLE 4: SUMMARY OF KEY ISSUES MAPPED BY JURORS AT THE END OF DAY 2

The final activity for the day was an indicative vote on the overall question put to the jury. This was designed to ‘take the temperature of the room’ and give the facilitation team a sense of which way the jury was leaning to help shape the structure of the deliberations planned for the next two days.

<b>Are there any circumstances under which a UK Government should consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions?</b>		
<b>Yes</b>	<b>No</b>	<b>Don't know</b>
16	2	3

TABLE 5: THE RESULTS OF THE FIRST INDICATIVE VOTE

After the results of the vote were revealed the jurors had an opportunity to discuss the outcome, consider what this meant for their further discussions and whether it gave rise to any additional conditionalities and/or priorities for the map. At this stage, some jurors challenged the framing of the question as being designed to deliver a positive response. They focussed on the inclusion of ‘any’ in relation to the circumstances in which a change should be considered and noted that this made it a very leading question that was difficult to say ‘no’ to.

This table discussion was followed by a plenary session in which jurors shared both their practical and their emotional responses to the vote and the result. A number of jurors expressed some confusion as to how the map related to the question and to their development of recommendations and time was spent discussing how the group would work together the next day to really explore the circumstances and the limits that would need to be in place, to be comfortable in taking a supporting position.

### **DAY 3**

Day 3 was focussed on dialogue and deliberation and was designed to ensure members were prepared for the process of determining their final recommendation the next day. In response to the members comments at the end of day 2 the lead facilitators had re-organised the ‘mind map’ overnight to help members begin to see how they could use it to focus their recommendations. Time was also allocated in the morning for the jurors to ‘step back’ and take time to reflect on everything they had heard. It was also an

opportunity to provide some clarifications regarding some of the emerging tensions and concerns in the room.

## THE DELIBERATIVE PROCESS

The day began with the Expert Leads Anna and Sasha re-capping the process so far and reminding jurors that their different experiences were considered expertise alongside the role of evidence in the process. In response to questions from the jurors, the recruitment process was also clarified and it was explained that, in seeking a sample who were representative of those who accesses genomic services, the jury was proportionately dominated by women (as there are more women who attend clinical genetics services than men).

In response to feedback from some jurors that minority voices were finding it difficult to explain the need to foreground equity in the discussions and to help others understand structural inequality and institutional racism, Anna and Sasha also gave a short overview of genetics and equality. This acknowledged that the workforce and those undertaking the research are predominantly white and middle class, thus accessing genetic counselling and participation in genetic research was easier for certain cultural, ethnic, socio-economic and intellectual groups. This means that genomic research and treatment tend to reflect wider structural inequalities. Jurors were asked to consider how they could foreground inclusivity in all their discussions as it had been a consistent underlying theme across the jury's discussions.

*“A lot of people here are coming from privilege and that has affected the outcome and the process. Representation doesn't necessarily mean inclusion. Future events should intentionally and accountably look into ensuring inclusion of minority voices, particularly from racialised backgrounds.”*

JUROR COMMENT DAY 3

### Revisiting the map

In the morning the jurors were also introduced to the reorganised map of issues, revised to help focus their attention on where there was most scope to make useful recommendations, recognising that many of the things that had been raised were outside the control of the UK government. It was also explicitly acknowledged that the map contained potentially conflicting sets of issues and priorities.

As part of the re-organisation of the map, the lead facilitators also reviewed and refined the ‘labels’ they had given to each of the themes and clusters (often done quickly as part of the plenary feedback process) to make them more fully reflect the ideas from the jurors that were encompassed within it. The reorganisation and categorisation of the issues are shown below.

After talking through the revised map there was an opportunity for questions and the ability to propose additions that jurors felt had been missed out. After discussion jurors confirmed that this now felt like an accurate reflection of the discussion over the course of the previous 2 days and were happy to use it as the basis for developing their recommendations.

<b>Why is the jury question being asked at this point?</b>	<b>Wider circumstances and areas for concern</b>	<b>Things we would want to see before there was a change in the law<sup>3</sup></b>
<ul style="list-style-type: none"> <li>• Enables families to make informed choices</li> <li>• Scientific progress is making this possible</li> <li>• Additional scientific benefits outside of gene editing?</li> <li>• Potential to target treatment</li> <li>• Reduction of suffering</li> <li>• Might reduce pressure on NHS</li> <li>• Could mean using fewer embryos</li> <li>• Identifying new conditions</li> </ul>	<ul style="list-style-type: none"> <li>• If other countries are doing it</li> <li>• We need to know it can be done safely</li> <li>• If time and money from government can be justified</li> <li>• If trust in decision makers is sufficient</li> <li>• If there is a fair ethical framework for studying effects</li> <li>• It must make a difference</li> <li>• Structural discrimination</li> <li>• External judgement</li> </ul>	<ul style="list-style-type: none"> <li>• Strictly limited to serious conditions and takes account of human rights questions</li> <li>• There is a clear and rigorous definition of serious condition - avoiding a hierarchy of conditions</li> <li>• Consent is clarified</li> <li>• Clarity on purpose of private sector</li> <li>• Equity in decision making</li> <li>• Equitable access to services</li> <li>• Support services are accessible</li> <li>• Genuine choice is retained - and there is</li> </ul>

<sup>3</sup> It was this column that the juror’s focused on most explicitly in identifying the focus of their recommendations.



		<p>support to choose not to</p> <ul style="list-style-type: none"> <li>• Have a clear plan and timeline</li> <li>• Ongoing engagement</li> <li>• Only do it if alternatives are not available</li> <li>• Ensure there is balanced evidence about the impact of conditions</li> <li>• Guarantees in place about insurance</li> <li>• Think through the unintended consequences</li> <li>• Ensure there is transparent and available information</li> <li>• Ensure personal information is kept private</li> </ul>
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**Revisiting the vote**

In response to the discussion after the indicative vote, the facilitation team decided that offering a more nuanced choice across a scale of 0-10 would be a productive way to develop the conversation and help jurors better understand the range of positions in the room. Jurors were asked to vote anonymously using the numbers on the scale to indicate their opinion on the question at this point in the deliberations.<sup>4</sup>

**Are there any circumstances under which a UK government should consider changing the law to allow intentional genome editing of human embryos for serious generic conditions?**

<sup>4</sup> Illustrative statements of position were included on the scale to assist members to position themselves consistently in relation to others.


Scale	Illustrative positioning statements	Votes cast
	10 <i>Government should be actively debating changing the law now</i>	2
	9	3
	8 <i>Government should consider changing the law, but only with strong guarantees and conditions</i>	9
	7	2
	6 <i>Uncertain but leaning towards YES, with conditions</i>	3
	5 <i>Undecided</i>	0
	4 <i>Uncertain but leaning towards NO</i>	0
	3	1
	2 <i>There may be some circumstances in the future where it could be acceptable for the government to consider changing the law, but not now</i>	1
	1	0
0 <i>In no circumstances, now or ever, should the UK government consider changing the law</i>	0	

TABLE 6: THE RESULTS OF THE SECOND INDICATIVE VOTE USING A SCALE FROM 0-10

After the results of the vote were revealed, jurors were asked if they wanted to share why they had voted as they had. Some jurors who volunteered that they had voted for the lower end of the scale shared that they felt there were still **too many structural issues embedded in society and its relationship to disability and that genome editing risked exacerbating these inequities**. They suggested that **some voices were missing from the room**, or were under-represented, notably those who had been disabled from birth as the result of a genetic condition.

Some jurors also identified **the need for more certainty and guarantees around eugenics and cosmetic use of gene editing before they would be comfortable with it being allowed**. Volunteers who shared they had chosen point 6 on the scale noted that they were still actively considering the evidence they had heard and the view of their fellow jurors.

Many of the jurors who shared that they had placed themselves at 7 or above on the scale were keen that research continues apace, as they were concerned that any **delay would mean we were taking viable options away from future generations**. They argued that as there are many serious genetic conditions, and it could take a long time for genome editing to be usable in a clinical setting, it was important to be able to get started. Additionally, some jurors were eager for genome editing to become a clinical possibility as soon as possible to **decrease and potentially avoid future suffering**.

“ The debate has to happen now. ”

JUROR RESPONSE TO THE SECOND INDICATIVE VOTE

“ I have a rare genetic condition and I live with excruciating physical and emotional pain. How much more suffering do you need to see before the law is changed and embryos can be edited? ”

JUROR COMMENT TO GENETIC COUNSELLOR DURING THE JURY

### Identifying areas for focus when developing recommendations

Following this vote, the jurors were given time at their tables to discuss the map of potential areas for focus in their recommendations, with particular focus on the things that they would want to see in place before any decision was made about changing the law. Each juror had the opportunity to identify up to 9 topics they believed were important to focus on. The results of this prioritisation exercise are shown below.

What would we want to see in place before there is a change in the law?	Votes
Guarantees of equity & diversity in decision making	18
Equitable access to services	17
Ensuring there is transparent and available information	17
Ensuring there is balanced evidence about the impact of conditions	15
Strict limits for serious conditions and taking account of human rights	14
There is a clear and rigorous definition of ‘serious’ condition	13
Support services are accessible	13
Ongoing engagement	12
Only do it if alternatives are not available	10
Genuine choice is retained - and there is support to choose not to	10
Thinking through the unintended consequences	9
Ensuring personal information is kept private	8
A clear plan and timeline	8
Clarity about the role of the private sector	8

Guarantees about insurance	7
Clarity around consent	4

TABLE 7: THE PRIORITISED THEMES

The prioritisation process had been intended to shortlist topics the jury would focus on. However, once the results were displayed the jurors discussed the fact that the lowest-rated issue was still prioritised by nearly 20% of the jury. It was agreed that, given this, all of the issues should be developed into recommendations.<sup>5</sup>

After lunch, jurors began the work of teasing out the rationales behind the prioritised themes. The methodology used at this stage was to split the 15 themes across 2 rounds of ‘open space’ sessions where jurors could choose what topic they worked on, rather than being assigned to table groups as they had been up till now. 7 themes were discussed in the first round and 8 in the second. In each of the ‘open spaces’ jurors were provided with the material that had been collected as part of the map (i.e., the range of post-it notes, comments and framings of the issues that had come from each table during day 1 and 2 that related to this topic) and a template worksheet to complete. The template, which had 3 prompts to help them collect and organise their ideas, is reproduced below. This was the start of the process of defining their final recommendations.

**Rationale:** Why is this an important factor to consider when thinking about changing the laws?

**Aim:** What do we hope to achieve by focusing on this?

**Basis:** What evidence are we basing this on?

BOX 3: TEMPLATE TO GUIDE THE FIRST STAGE OF RECOMMENDATION DEVELOPMENT

Once the open space rounds were complete, jurors were invited to review the work others had done on the themes they had not worked on and add post-it notes to indicate

<sup>5</sup> During this discussion the jurors agreed that the two issues relating to defining ‘serious’ conditions and limiting to ‘serious’ conditions could be combined under the title ‘Applicable Conditions’, leaving 15 issues to develop into recommendations.

whether they thought any issues were missing. This work would be used on day four to finalise the recommendations.

## SUMMARY OF KEY OUTPUTS

Before starting work on defining and refining their recommendations, jurors were invited to consider what cross-cutting core principles had been important during their deliberations up to this point. This conversation led to the development of a set of underpinning values which they agreed should inform the development of all the recommendations.

- |  |   |
|--|---|
| <ul style="list-style-type: none"><li>• Fairness</li><li>• Inclusivity and Diversity</li><li>• Lived experience / co-production</li><li>• Person centred not profit centred</li><li>• Future proof the process</li></ul> | <ul style="list-style-type: none"><li>• Choice</li><li>• Transparency across the board</li><li>• Do no harm</li><li>• Remain open and accountable</li></ul> |
|--|---|

BOX 4: VALUES THAT SHOULD UNDERPIN THE JURY'S RECOMMENDATIONS

## DAY 4

Day 4 was planned as entirely devoted to deliberation to enable members to finalise their recommendations and present them to the Director of Wellcome Connecting Science Prof Julian Rayner.

## THE DELIBERATIVE PROCESS

In response to a request from some jurors, as day 3 had included some difficult conversations around the definition of 'serious conditions', this topic became a focus for discussion in the morning and Anna gave a short presentation summarising a number of different proposals by scientists, researchers and policy makers to define the term 'serious conditions'. This was discussed both in the context of the question the jury had been asked to address and the jurors' own wider lived experience. Many jurors returned to the question of [who it is who makes these decisions](#) and what [value is given to the voices of those with lived experience](#). They asked if institutions like the Human Fertilisation and Embryology Authority (HFEA) could undertake more patient and public involvement and engagement (PPIE), rather than just accepting written submissions.

They felt it was important that they carried out lived experience engagement, especially with edge cases.

Some jurors felt that lived experience and/or diverse perspectives were not reflected in the current definitions. They asked what the process was for developing the definitions and how they were used in practice. They questioned how guidance was updated and disseminated and asked if pressures on the NHS would prevent efficient and effective sharing of updates.

They suggested that definitions should replace 'serious' with 'suffering', but acknowledged this was subjective, hard to define, and extended beyond the individual with the genetic condition. They also recognised [that because genome editing takes place before birth, can it really take the suffering of a child who does not yet exist into account?](#) Most jurors agreed that any 'list' regarding severity should not be static and asked if it could be regularly [revised based on treatments or ability to live with a condition.](#)

The contrast in views in the room was made particularly apparent at this stage, with those currently living with disease feeling that they were being identified as having a 'serious' or 'not serious' condition, and with that label being told they were either at risk of increased morbidity (in itself a term they were unclear on the definition of) or that their conditions were not severe enough to be included in the definition of serious.

“ Does that seriousness reduce the value of my life? I don't think it does. ”

JUROR REFLECTION IN PLENARY.

This emphasised the differences in opinion between those living with a genetic condition and those who were parents of a child who had died of a genetic condition. One juror offered this reflection on why this divide exists within the rare disease community.

“ Children with rare diseases feel poked and prodded and basically exploited by the medical profession. Hopefully this is a situation that is improving, but certainly disabled adults now, they reject everything to do with the medical model of anything because they got to 18 and realised, I don't have to do this anymore and just pushed all medical care or as much as they possibly could out of the way to try and get on with their life. And that means that in the rare disease space you end up with a skewed picture of the cause. It's mostly parents. ”

JUROR REFLECTION AT THE CLOSE OF THE PROCESS.

### Co-drafting recommendations

In the later part of the morning the jurors began working together to draft what would become their final recommendations. Jurors were again invited to select which recommendation they wanted to work on using an open space methodology. New template worksheets were provided for jurors to support them to develop the 15 recommendations, drawing on the completed worksheets from day 3. Jurors worked on two recommendations each.

**Framing question:** *If the UK government was to consider changing the law to allow the intentional genome editing of human embryos for serious genetic conditions, we believe that there are things that need to be in place before any decisions are made.*

**There needs to be...** (Action):

**Because...** (Aim):

**So that...** (Outcome):

BOX 6: TEMPLATE TO GUIDE RECOMMENDATION DRAFTING

Once the work was completed on each draft text they were displayed within the room. Jurors were asked to review all the recommendations, with the option of indicating whether they 'liked it', could 'live with it' or thought something needed to be changed. If they felt something needed to be changed, they added a post-it note explaining what they felt needed to be changed or added. While the plenary discussions on day 4 were able to confirm that a variety of simple changes and additions were agreed to the draft recommendations there were a variety of more detailed, or controversial, proposals for inclusion or amendment that were agreed to be put to an anonymous vote after the meeting.

The co-drafted text of each recommendation, plus the text of each amendment proposed by jurors during the review process, was circulated to jurors a week after the jury had met. They were invited to vote online, using Survey Monkey, on whether they 'liked', 'could live with', or 'disliked' each draft recommendation. They were also asked to vote on whether they agreed with the amendments proposed to various recommendations. 20 of the 21 jurors took part in this vote, although not all jurors voted on all recommendations. The results of this process are presented in the next section of the report.

## FINAL VOTE ON THE JURY QUESTION

Before presenting their recommendations to Wellcome Connecting Science the jurors were invited to vote, for the last time, on the main question posed to them at the beginning of the jury. They voted using a 0 -10 scale to ensure that the nuance of their views was captured.<sup>6</sup>

**Are there any circumstances under which a UK government should consider changing the law to allow intentional genome editing of human embryos for serious generic conditions?**


Scale	<i>Illustrative positioning statements</i>	Votes cast
 10 9 8 7 6 5 4 3 2 1 0	<i>Government should be actively debating changing the law now</i>	<b>7</b>
		<b>6</b>
	<i>Government should consider changing the law, but only with strong guarantees and conditions</i>	<b>4</b>
		<b>0</b>
	<i>Uncertain but leaning towards YES, with conditions</i>	<b>2</b>
	<i>Undecided</i>	<b>0</b>
	<i>Uncertain but leaning towards NO</i>	<b>0</b>
		<b>0</b>
	<i>There may be some circumstances in the future where it could be acceptable for the government to consider changing the law, but not now</i>	<b>2</b>
		<b>0</b>
	<i>In no circumstances, now or ever, should the UK government consider changing the law</i>	<b>0</b>

TABLE 8: THE RESULTS OF THE FINAL VOTE ON THE JURY’S OVERARCHING QUESTION

<sup>6</sup> Illustrative statements of position were included on the scale to assist members to position themselves consistently in relation to others.



## THE JURY'S RECOMMENDATIONS

The citizens jury considered, over 4 days, the following question:

**Are there any circumstances under which a UK Government should consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions?**

When polled at the end of the process the majority of the jurors agreed (17 to 4) that the government should consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions, and most felt that these discussions should be beginning now.

The views that informed this conclusion were nuanced and complex and, whilst the majority expressed broad support for the clinical application of the technology, there were limitations and conditions attached to this.

In developing and agreeing their final recommendations the juror's participated in a 5-stage process during days 3 and 4 that was driven by the prompt statement:

**If the UK government was to consider changing the law to allow the intentional genome editing of human embryos for serious genetic conditions we believe that there are things that need to be in place before any decisions are made.**

The 5 stages, the details of which are described in detail in the previous section of this report, were designed to maximise the legitimacy of the conclusions by seeking to identify where there was the strongest level of consensus between members. The stages can be summarised as:

- a. Jurors choosing 1 of the key areas of focus from the 'mind-map' and working to outline of the purpose of the recommendation i.e. what it is hoping to achieve
- b. Jurors co-drafting (in small self-selecting groups) the text of the recommendation to capture the circumstances and guarantees that jurors felt would need to be in place in order to support the UK changing the law to allow genome editing of human embryos
- c. An opportunity for the rest of the jury to comment on the drafts developed by each of the small groups and offer suggestions for changes, additions and/or clarifications
- d. Reflection on the comments and suggestions and time for re-drafting

- e. A final electronic vote by the jurors indicating their support for each recommendation, and the proposed amendments, conducted in the week after the jury had met.

The 15 recommendations are presented below, these are what the jury decided needed serious consideration when discussing a change in the law to allow the intentional genome editing of human embryos. They have been grouped into 4 themes, developed as part of our analysis of the jurors' deliberations after the event to help readers understand the priorities of those involved in the deliberations.

In each case the text of the recommendations drafted by jurors was developed in response to the following prompts:

- There needs to be... (*the action needed*)
- Because... (*the problem identified*)
- So that... (*the difference made, or the outcome hoped to be achieved*)

## RECOMMENDATIONS

This section presents the final recommendations as developed by the jury. The summary text we have used to theme the recommendations is presented first, followed by the content of the specific recommendation as written by members.

The rate of support indicates the number of members who supported the content of the overall recommendation in a vote conducted after the meetings. Where there were proposals for amendment that were not agreed by the majority of the jurors these have been noted below the recommendation for reference.<sup>7</sup>

### THEME 1: DEVELOP A CLEAR PLAN AND TIMELINE IF DISCUSSIONS BEGIN ABOUT CHANGING THE LAW SO THAT THE POTENTIAL BENEFITS OF GENOME EDITING CAN BE MADE AVAILABLE FOR FUTURE GENERATIONS.

The recommendations grouped under this theme include (in no particular order):

- 1. Develop a clear plan and timeline if discussions begin about changing the law so that the potential benefits of genome editing can be made available for future generations.**

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<sup>7</sup> Amendments which were supported by the majority of jurors have been added as part of the main body of the recommendation in *italics*.

(RECOMMENDATION SUPPORTED BY 19 OF 21 JURORS)

*There needs to be...* A clear, transparent and detailed plan and timeline (for how this change happens) if discussions begin about changing the law so that the potential benefits of genome editing can be made available for future generations. For accountability, this must include inclusion in the planning and delivery, not just the end consultation and decision making, and ongoing review of who in society is being marginalised.

*Because...* We need to maintain momentum and progress towards clinical applications of genome editing whilst ensuring the inclusivity of diverse perspectives (both professional and patient). This also needs to be done diligently.

*So that...* The potential benefits of genome editing can be made available for future generations. And so that policy makers have the tools to make an informed decision.

## **2. Ensure equity and diversity are central to all decisions about whether and how to proceed**

(RECOMMENDATION SUPPORTED BY 20 OF 21 JURORS)

*There needs to be...* intentional and accountable processes of consultation and recruitment that identify missing voices and take action to include and empower them. For accountability, this must include inclusion in the planning and delivery, not just the end consultation and decision making, and ongoing review of who in society is being marginalised.

*Because...* Existing structural barriers must be acknowledged and challenged. Evidence exists that barriers are real and enduring and good decision making should not perpetuate those barriers.

*So that...* Social change and justice and fairness are central. There is equity in access, opportunities, support, engagement and education in the decision making process. So that we are making space to include views from minority groups, even when these are dissenting or inconsistent with a final decision - People need to be heard.

## **3. Avoid unintended consequences and the risk of further marginalising already marginalised groups.**

(RECOMMENDATION SUPPORTED BY 19 OF 21 BY OF JURORS)

*There needs to be...*

- Recognition of the potential for unintended consequences.

- Good quality research.
- International collaboration.
- Assurance that investment would continue in existing services.
- Open, transparent discussion.
- Regular review of developments.

*Because...* The existing structural barriers relating to social inequities cannot be ignored, but rather must be acknowledged and challenged. Evidence exists that barriers are real and enduring and good decision making should not perpetuate those barriers.

Inclusion in the planning and delivery, not just the end consultation and decision making, and ongoing review of who in society is being marginalised [is important]. We need to maintain momentum and progress towards clinical applications of genome editing whilst ensuring inclusivity of diverse perspectives (both professional and patient). This also needs to be done diligently.

*So that...* The potential benefits of genome editing can be made available for future generations. And so that policy makers have the tools to make an informed decision.

*It is also important to minimise the risk of potential additional discrimination in society for disabled people in general, not just those with genetic disorders.*<sup>8</sup>

#### 4. Ensure ongoing engagement between decision makers and users of services.

(RECOMMENDATION SUPPORTED BY 20 OF 21 JURORS)

*There needs to be...* A commitment to co-production<sup>9</sup> to facilitate ongoing decision making.

*Because...* In order to avoid power imbalance in decision making processes there needs to be genuine co-production featuring:

- Active listening
- A variety of voices and
- Iterative processes that builds trust and transparency.

---

<sup>8</sup> The text in italics was a proposed addition to the content of this recommendation voted on after the jury meetings had concluded. It was agreed by the majority of jurors, with the votes cast being: *Yes:15, Can live with it: 4, No: 1.*

<sup>9</sup> The term co-production refers to a way of working where service providers and users work together to reach a collective outcome. The approach is value-driven and built on the principle that those who are affected by a service are best placed to help design it. Ref: [Involve](#).

We need to maintain momentum and progress towards clinical applications of genome editing whilst ensuring inclusivity of diverse perspectives (both professional and patient). This also needs to be done diligently.

*So that...* Inclusivity and diversity are built into the templates and processes from the start to ensure those who are directly involved and impacted are part of the ongoing process, and 'decision makers' are held to account.

## **THEME 2. PUT IN PLACE EFFECTIVE SUPPORT TO ENSURE EQUITABLE ACCESS TO TREATMENT**

The recommendations grouped under this theme include (in no particular order):

### **5. Develop a clear framework for giving and obtaining consent so that a balanced decision can be taken in the best interests, and respecting the rights of, the embryo, child and parents.**

(RECOMMENDATION SUPPORTED BY 20 OF 21 JURORS)

*There needs to be...*

- A clear framework around rights to give and obtain consent efficient enough to avoid delays which may impact the likelihood of successful IVF.
- A way to ensure that whoever gives consent is fully informed by unbiased and balanced information based on scientific facts and diverse lived experience.
- A documented process about how and why the decision had been made and records accessible to the child when requested.

This will ensure a fair process based on diverse lived experience, taking into consideration both parental needs and the rights of the child.

*Because...* In order to avoid power imbalance in decision making processes there needs to be genuine co-production featuring:

- Active listening
- A variety of voices and
- Iterative processes that builds trust and transparency.

*So that...* A balanced decision can be taken in the best interests and rights of the embryo, child, and parents.

**6. Ensure genuine choice so that there is an option to say no to the technology and be in no way disadvantaged.**

(RECOMMENDATION SUPPORTED BY 19 OF 21 JURORS)

*There needs to be...* clearly defined ways for families to be able to opt-in or out., with available alternatives. *This support should be offered across the board, including for disabled people and their families.*<sup>10</sup>

*Because...* Families should not feel pressured into a decision they are not comfortable with. Families need access to information at all points of the process.

*So that...* Families are supported and valued throughout the process. They are able to leave the process at any time, with no risk of excess pressure or recriminations and with confidence that they will be able to access alternative options.

**7. Provide fair and balanced evidence about genetic conditions so that people understand what it is like to live with the condition and have all the information they need to make an informed decision about editing.**

(RECOMMENDATION SUPPORTED BY 19 OF 21 JURORS)

*There needs to be...* a space dedicated to supporting families with a history of genetic conditions with crowd-sourced and clinical information about that condition. This process should be efficient enough to avoid delays which may impact the likelihood of successful IVF. This support should be offered across the board including for disabled people and their families.

It would involve building relationships with, and leading engagement and signposting to, genetics organisations and charities and needs to connect the following groups together:

- Human Fertilisation and Embryology Authority
- GPs
- Genetic counsellors
- Support groups and charities for people with genetic conditions

The information provided should include clinical evidence as well as life experience, but should not be confined to medical information but rather should extend to social impacts - positive and negative.

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<sup>10</sup> This final sentence was added during the review phase and agreed by members for inclusion in the recommendation. Votes. Yes: 16. Can live with it: 3. No: 1.

*Because...* These organisations can provide

- Up to date information
- Lived experiences
- Options
- Support
- Information about the range of services available

*So that...* People understand what it is like to live with the condition and have all the information they need to make an informed decision. Not all conditions have support groups, and some charities can be ineffective in providing support. Organisations providing support about the impact of genetic conditions should build relationships with genetic advice providers to improve communication and availability of information. Genetic charities also may require financial support.

**8. Ensure support is available, i.e. support services are accessible to everyone and people’s physical, emotional and mental health are safeguarded.**

(RECOMMENDATION SUPPORTED BY 19 OF 21 JURORS)

*There needs to be...* Resources to support services that are equally available and accessible to all, better coordination of care and sufficient genetic counsellors.

*Because...* Current pathways to services are not suitable or efficient because there is a disparity of access based on diversity discrimination and other factors e.g. location.

*So that...* Support services are accessible and available to all and peoples’ physical, emotional and mental health is safeguarded (do no harm principle).

**9. Provide transparent information, e.g. a hub where patients and families can have access to all information regarding embryo editing and a ‘one-stop shop’ for information on genomics.**

(RECOMMENDATION SUPPORTED BY 20 OF 21 JURORS)

*There needs to be...* A hub where patients and families can have access to all information regarding government decision making/outcomes, genomic research, data, and all parties involved in the decision making process.

Medical governing bodies (e.g. GMC) need to be more accountable across the board to improve transparency. There should be transparency about the results of

genome editing including publicly available data on numbers, conditions, safety etc.

*Because...* Some information is outdated [and] this would create a ‘one-stop shop’ for genetic/genomic information.

- To encourage regulation across decision makers and service procurement thus giving patients and families access to information and data.
- To further regulate relationships between NHS, big pharma and genetic companies and reduce unethical practice.

*So that...* Trust and confidence in the NHS can be improved. Families can make informed decisions. There is a language that is easier to interpret.

## **10. Ensure equitable access to publicly funded services centring on the value of everyone’s right to treatment to try and have a child (regardless of age, ability, socio-economic status, or ethnicity).**

(RECOMMENDATION SUPPORTED BY 17 OF 21 JURORS)

*There needs to be...* Equitable access that is:

- Available free on the NHS.
- Centring the value of everyone’s right to treatment to try to have a child (regardless of age, ability, socio-economic status or ethnicity).
- Not judgemental regarding parenting ability and relationship status.
- Intentional and accountable measures to address systemic racism.
- Across all 4 UK countries (in terms of funding, accessibility and timelines).

*Self-referral and other models of referral (to avoid blocking by gatekeepers) should be explored.<sup>11</sup>*

*Because...* The current system is inequitable.

*So that...* Everyone has equitable access.

We would also note that these rights, if they do exist, do not apply equally to disabled people.

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<sup>11</sup>A proposal was made by jurors to remove the reference to self-referral in this recommendation. Following the vote it has been retained.  
Votes: Keep: 11. Can live with it: 4. Remove: 5.



## THEME 3. PROTECT THE RIGHTS EQUALLY OF THOSE WHO DECIDE TO PROCEED OR NOT TO PROCEED WITH TREATMENT

The recommendations grouped under this theme include (in no particular order):

### 11. Ensure equal access to insurance and no discrimination on the basis of genetic information, i.e. if you are an 'edited person' you should be able to access the same insurance as other people who have not had editing.

(RECOMMENDATION SUPPORTED BY 20 OF 21 JURORS)

*There needs to be...* A change in legislation to ensure that genome editing status becomes a protected characteristic.

This recommendation is founded on:

- An assurance that insurance companies can't have mandatory access to your genetic information (i.e. if you are an 'edited' person).
- That demands/pressure to disclose or give access to genetic information (in order to have insurance) is not prejudicial.
- That disclosure of genome editing status does not create discrimination.

*Because...* There needs to be a guarantee that discriminatory practices will not be permitted.

*So that...* We avoid any detrimental impact of editing/not editing and e limit the potential for discriminatory practices.

*Jurors also identified two further questions which policy makers will need to consider:*

- *If genome editing is defined as a protected characteristic, should it include carriers of all genetic conditions?*
- *If genome editing is defined as a protected characteristic, for how many generations should it apply to?*

### 12. Ensure embryo editing is available via publicly funded health services and obtain clarity about the purpose of the private sector with respect to delivery of such services.

(RECOMMENDATION SUPPORTED BY 19 OF 21 JURORS)

*There needs to be...* Guidelines, controls and stops set by an overarching governing body (e.g. GMC) to prevent clinicians profiteering because NHS patients suffer.

*Because...* Currently, we perceive that private doctors are able to practice with 'free rein' with limited scrutiny and accountability. Put controls in place to stop clinicians in the private sector from profiteering from patient suffering.

*So that...* There are guidelines, controls and stops to override this practice and ensure fair treatment, with a view to enhancing dignity for patients, improving accountability and robust and transparent protocols.

Note: this recommendation currently focuses on doctors and clinicians in private practice. It does not include big pharma and private genetic companies, but it could.

### **13. Keep personal information private, with due consideration to protecting a parent's right not to disclose if they have had embryo editing and a child's right to not declare this either.**

(RECOMMENDATION SUPPORTED BY 20 OF 21 JURORS)

*There needs to be...* Legislation that protects the individual's right to privacy, with clarification of the relative rights of the parent and the child. Data used for research should be used correctly and ethically.

*Because...* There is currently a potentially unresolved conflict between the interests of the child and the parent. We also need to prevent the misuse of data (and to ensure consent to use data is given clearly).

*So that...* Children are ensured a protected right to their own health information in law and in practice.

## **THEME 4. DEVELOP AN EQUITABLE PROCESS AND FRAMEWORK TO REDUCE THE WIDER SOCIAL INEQUALITIES AND THE POTENTIAL FOR HARM**

The recommendations grouped under this theme include (in no particular order):

### **14. Ensure genome editing is only available if there are no alternatives.**

(RECOMMENDATION SUPPORTED BY 15 OF 21 JURORS)

*There needs to be...* A mechanism/process to ensure other alternatives to embryo genome editing have been considered and that this is performed in a timely way to ensure it fits with the IVF/ PGD timeline.

Under the following conditions:

- For people who cannot produce embryos without the genetic condition.
- PGD has failed and been exhausted within a defined time limit.
- Strong enough human reasons why PGD is not available i.e. psychological harm.

- *For serious conditions/syndromes where PGD should not be considered.*<sup>12</sup>

*Because...* We need to avoid the technology being used inappropriately. We need to give an option to those who do not have any other.

*So that...* There is transparency for society as a whole as to who is able to access genome editing. And so that it can proceed at a pace that ensures that 'reproductive years' are not wasted.

## **15. Create a clear framework to identify genetic conditions for which genome editing is acceptable.**

(RECOMMENDATION SUPPORTED BY 20 OF 21 JURORS)

*There needs to be...* Clear and transparent regulation of a sufficiently flexible framework to identify genetic conditions/syndromes that meet the criteria to apply for treatment. This needs to take account of the risk that society attempts to eliminate disability negatively impacting those already living with a disability, born with a disability or impairment in the future, or becoming disabled through accident.

*Because...* It is essential that the technology cannot be misused for enhancement purposes or for personal gain.

- a) We acknowledge that people's choices and disabilities are already judged and genome editing risks making this worse. We are concerned that this is the start of a 'slippery slope'.<sup>13</sup>*
- b) We will never eradicate disability and this debate risks worsening society's judgement.*
- c) We want to acknowledge the risk of creep that has occurred with PGD.*

*So that...* The potential impact on society is mitigated. The technology is not used inappropriately, for example for cosmetic reasons. The regulation applies equally to the NHS and private sector in the UK.

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<sup>12</sup> This final point was added during the review phase and agreed by members for inclusion in the recommendation. Votes. Yes: 12. Can live with it: 4. No: 2

<sup>13</sup> These final points were proposed during the review phase and agreed by members for inclusion in the recommendation. Votes on a) Yes: 9. Can live with it: 8. No: 3, Votes on b) Yes: 14. Can live with it: 3. No: 3 Votes on c) Yes: 9. Can live with it: 8. No: 3

## APPENDIX 1 - OVERSIGHT GROUP

### TERMS OF REFERENCE

#### INTRODUCTION

Wellcome Connecting Science and Involve are partnering to deliver a [Citizens Jury](#) on heritable human genome editing for clinical purposes. This jury aims to produce an output which will be useful to policy makers in the UK wanting to better understand public perspectives on this issue. The jury is also part of a wider project, led by the University of Canberra, to run a [Global Citizens' Assembly on Genome Editing](#).

The project will have an oversight group to support the project team to ensure that the jury, its framing, the questions it is asked, and the materials and experts involved in briefing the jurors are as unbiased as possible.

#### PROJECT AIMS

- To provide an insight into the perspectives of a group of patients with heritable conditions, and their parents and carers
  - what they think about benefits, risks and wider harms emerging from heritable human genome editing.
  - what values and principles they bring to bear as they engage with the tensions and trade-offs exposed by the technology.
- To identify any policy redlines.

In order to:

- Support policy makers, researchers and wider civil society to better understand informed public perspectives on the issue of heritable human genome editing; and
- Support and inform the Global Citizens' Assembly.

#### OVERSIGHT GROUP ROLE

The project will take place between February 2022 and September 2022. Advisory Group (OG) members will be asked to attend three meetings as well as give advice on their areas of expertise on an ad hoc basis.

It is expected that the Advisory Group will comment on the following:

- The overall framing of the Jury and key questions to be addressed.
- Background/stimulus materials (ensuring it is comprehensive, balanced and neutral and accessible to a lay audience).
- The balance of experts invited to contribute to the Jury.
- Communications strategy.
- Outputs from the dialogue exercises including written reports.

OG members will receive papers for all meetings of the group two weeks beforehand.

The OG will also advise on:

## **IMPARTIALITY**

- Ensuring that the dialogue process is balanced and perceived as such by the outside world.
- Supporting the overall process and ensuring that the right questions have been asked at the right time and that the right people are in the room.

## **SUPPORT FOR THE PROJECT PROCESS**

- Helping to develop the criteria on which the success of the project is going to be judged. OG members are often members of key organisations who will use the outputs of a dialogue, so help from them on what success “looks like” is useful.
- Acting as a sounding board for potential activities or decisions about the process or content.
- Giving advice when things get challenging for the project manager – dealing with uncertainties, providing independence where needed, and advice on finding and contacting the right people quickly.

## **AMBASSADOR ROLE**

- Providing informed input to and feedback from the dialogue throughout the project from the set-up stage through to the dissemination of findings and impact of outcomes.
- Members are key parties or stakeholders, so when it comes to dissemination of the results of a dialogue they often own or can influence policy change in relevant institutions.
- Providing a credible independent voice for the process, if needed – quotations explaining the integrity of the process can be provided to the media; in the case of controversy, media interviews could even be arranged.

The role of the Group is advisory; it has no decision-making responsibilities. Wellcome Connecting Science and Involve commit to reporting back on how they have acted on the advice of the group.

## **Timeline**

Three meetings of the OG are planned:

- June 13<sup>th</sup>, 3-5pm
- August 4<sup>th</sup>, 9-11am
- October 19<sup>th</sup>, 9-11am

It is expected that the OG meetings will take place online. The Jury will take place from 13<sup>th</sup>-16<sup>th</sup> September. It will be face-to-face at the Wellcome Genome Campus, Cambridge. OG members will be invited to observe Jury sessions should they wish to.

## MEMBERS

- **Mark Bale** - Department for Health and Social Care/ Genomics England (until April 2022)
- **Cath Joynson** - Nuffield Council on Bioethics
- **Sarion Bowers** - Wellcome Sanger Institute
- **Nick Meade** - Genetic Alliance UK

## MEETING CONTENT

### Meeting 1<sup>st</sup> – 13<sup>th</sup> June

- Background paper on context (global jury) - paper Involve
- Background paper on recruitment sample frame - paper WCS
- Input into framing and questions - paper Involve
- Input into background required by jury - paper WCS (outline (+content?) of handbook)
- Input into shortlist of experts - paper WCS
- Input into outline process plan - paper Involve

### Meeting 2<sup>nd</sup> – 1<sup>st</sup> August

- Input into evaluation questions - paper MH/NC
- Final comments on evidence pack - paper WCS
- Final input process plan - paper Involve

### Meeting 3<sup>rd</sup> – 17<sup>th</sup> October

- Comment on report draft - paper Involve

## APPENDIX 2 - EXTERNAL, INDEPENDENT EVALUATION OF THE CITIZENS JURY

The citizens jury project was commissioned by Wellcome Connecting Science, Wellcome Genome Campus, Cambridge, UK. Wellcome Connecting Science's mission is to enable everyone to explore genomic science and its impact on research, health and society. They in turn commissioned experts in the delivery of citizens jury to independently evaluate the quality of the jury process. This was done by staff from the Centre for Deliberative Democracy at the University of Canberra and KU Leuven. Their executive summary on the jury is as follows:

### EXECUTIVE SUMMARY

This evaluation uses a deliberative systems framework. A deliberative systems framework considers democratic innovations like citizens' juries as one part of a wider constellation of institutions, practices, and actors that shape public discourse and decision-making. In practice, this involves the evaluation of both internal and external quality, and the integrity of the process.

- **Internal quality:** Having a jury comprised of people with lived experience is innovative and provided the opportunity for jurors to build connection and empathy across their experiences. It [AM1] also highlighted the diversity of lived experience and the reality of structural inequalities.
- **External quality:** The jury and the short film connected to it have the potential to input into policymaking and spark broader public debate. Most jurors felt that the presence of cameras and wearing a mic during deliberations did not affect their behaviour. A briefing is also being prepared for policymakers.
- **Integrity:** Responsiveness to jurors' queries and needs was the organisers' key integrity practice. Also notable was the clarity of the experts' role as 'conversation partners' and not 'all-knowing experts' who imposed views on jurors. The data collected demonstrated that the citizens jury conforms to norms of deliberative integrity and ethical conduct.