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**DELIBERATIVE DEMOCRACY  
AND GLOBAL GOVERNANCE**



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**CANBERRA**

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# **UK CITIZENS' JURY ON HUMAN EMBRYO EDITING**

## **EVALUATION REPORT**

# ABOUT THE AUTHORS

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# PREFACE

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‘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 was the question 21 patients and family members affected by genetic conditions were asked in a citizens’ jury held at the Wellcome Genome Campus from September 13 to 16, 2022. Over four days of deliberations, jurors talked to experts, deliberated in small groups and plenary sessions, experienced varying levels of emotions, and, in the end, produced collective recommendations.

All jurors concluded that the UK government should *consider debating* changing the law on this matter to allow intentional genome editing of human embryos for serious genetic conditions. However, the overall views were nuanced with a spread of views across a 0-10 scale. A minority of jurors felt that this debate should not happen now, in current circumstances, whilst others felt that strong conditions needed to be in place before consideration. To this end, jurors also developed a range of conditions that they felt should be in place in order for the government to consider changing the law, as well as recommendations to guide future decision-making on genome editing.

Citizens’ juries are increasingly used around the world. By giving a diverse group of people the time and space to learn about complex topics, exchange arguments and reflect on a variety of perspectives, advocates claim that these processes generate thoughtful recommendations to inform policymaking and conversations in the public at large. At the same time, they remain a relatively marginal practice and more evidence is needed to demonstrate their impact and value in policymaking processes.

In this evaluation report, we examine the citizens’ jury from the perspectives of the jurors, facilitators, organisers, and experts. Using quantitative and qualitative data, we present key findings, actionable recommendations, and points for reflection about the conduct of the UK Citizens’ Jury on Human Embryo Editing.

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# EXECUTIVE SUMMARY

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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 evaluation of both internal and external quality, and the integrity of the process.

- **Internal quality:** Having a jury comprised of people with lived experience provided the opportunity for jurors to build connection and empathy across their experiences. It 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. 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 experts' role as 'conversation partners' and not 'all-knowing experts' who imposed views on jurors. Most jurors felt that the presence of cameras and wearing a mic during deliberations for the purposes of the documentary did not affect their behaviour.

We conclude our report by putting forward recommendations for similar citizens' juries.

# PURPOSE OF EVALUATION

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We conducted an independent assessment on the quality and integrity of the citizens' jury on genome editing to:

1. Track the citizens' jury across the four days to identify adjustments that were needed to achieve its purpose and meet jurors' needs. We conducted a short survey at the end of each day which asked jurors how they felt during the day, if they felt they could contribute effectively and why, and if anything could be improved. We processed the data immediately and passed it onto organisers each evening. We also took part in daily debriefs with organisers and facilitators where we could share observations from plenary sessions, table discussions, and jurors' reflections.
2. Uphold transparency and accountability to participants, funders, the research community, public authorities, and the wider public by publishing the outcomes of the evaluation.
3. Foster iterative learning to improve the design, implementation, and monitoring of similar programmes. This is especially important for the UK Citizens' Jury on Human Embryo Editing because the jurors were not a random sample of the wider population, but a sample of people with lived experience of genetic conditions. It is thus imperative to learn from this specific application of the Citizens' Jury method to understand its usefulness and limits. To this end, at the end of each section poses points for reflection raised by this jury that should be considered moving forward.

# UK CITIZENS' JURY ON HUMAN EMBRYO EDITING: DESIGN FEATURES

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## Commissioning body

Wellcome Connecting Science

## Implementation partners

Involve UK	Lead facilitation, process design, and documentation of jury recommendations
Genetic Alliance UK	Recruitment
Wellcome Connecting Science and The Change Agency	Table facilitation
Monster Films and Lambda Films	Filmmakers
University of Canberra & KU Leuven	Independent evaluators

## Purpose of the Jury

To contribute to shaping the public conversation and decision-making about genome editing technologies around the world, particularly the UK.

## Remit

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?

## Recruitment

24 jurors were selected to represent the diversity of the patient community, carers and parents of people affected by serious genetic conditions. 21 participated in the jury, with three jurors unable to attend due to their condition.

## Expert Leads

- Sasha Henriques, Wellcome Connecting Science
- Prof Felicity Boardman, University of Warwick

## Process plan

Day 1	Day 2	Day 3	Day 4
<p>Talk to specialists about the basic science, law and policy</p> <p>Start to develop a map of issues jurors want to turn into recommendations</p>	<p>Talk to specialists with different views on issues</p> <p>Develop the map of issues and take a provisional vote to 'temperature check' the jury on the question</p>	<p>Develop recommendations</p>	<p>Finalise recommendations and take the final vote</p> <p>Present findings</p>

## Citizens' jury final vote

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?

Option	No. of votes
0 In no circumstances now or ever should government consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions	0 votes
1	0 votes
2 There may be some circumstances in the future that it would be acceptable for government to consider changing the law, but not now	2 votes
3	0 votes
4 Uncertain, but maybe leaning towards no	0 votes
5 Undecided	0 votes
6 Uncertain, but maybe leaning towards yes with conditions	2 votes
7	0 votes
8 Government should consider changing the law, but only with strong guarantees and conditions	4 votes
9	6 votes
10 Government should be actively debating changing the law to allow intentional genome editing of human embryos for serious genetic conditions <b>now</b>	7 votes



## Report of the UK Citizens' Jury on Human Embryo Editing

Wellcome Connecting Science and Involve UK prepared a report summarising the recommendations and insights participants put forward in the jury. See: Wellcome Connecting Science (2022) Report of the UK Citizens Jury on Human Embryo Editing. 13th-16th September. Collated by Involve. Accessed from <https://societyandethicsresearch.wellcomeconnectingscience.org/project/uk-citizensjury-on-genome-editing/>

## From 'UK citizens' jury on genome editing' to 'UK citizens' jury on human embryo editing'

The original title of this project was 'Citizens' Jury on Genome Editing of Embryos: Formulating a UK Community Response.' This title appeared in the Participant Information booklet, Consent form and Invitation to participate. This title was shortened to 'UK citizens jury on genome editing' for the information booklet that jurors received on the first day of the jury and for the banners that appeared in the conference centre on the event. The post-jury report prepared by Involve was titled 'UK citizens' jury on human embryo editing' as this more accurately reflected the scope of deliberation. All jurors were given the opportunity to endorse and sign-off the report and all 21 have now done this.

# EVALUATION FRAMEWORK

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The citizens' jury on genome editing sought to generate insight into the perspectives of a group of genetics patients and their relatives. The recommendations from the jury aimed to provide credible input to support policymakers, researchers, and wider society to understand informed patient perspectives on the issue of human embryo genome editing.

Our 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.<sup>1</sup> This is a suitable evaluation framework considering the project's aim of connecting the citizens' juries' output to a range of stakeholders.

## There are three components to our evaluation.

- **Internal quality:** the extent to which the process upheld the principles of inclusiveness and deliberativeness.
- **External quality:** the different ways in which the jury was connected to the wider public sphere, researchers, and policymakers.
- **Deliberative integrity:** the extent to which the process upheld norms of ethical conduct in its design, implementation, and governance.

## We based our evaluation on the following data:<sup>2</sup>

- Short paper-based questionnaires at the end of each day to check in with the jurors and a longer questionnaire on the final day to have a holistic assessment of their experience.
- An online questionnaire for the organisers to facilitate reflection on the process a week after the jury. By organisers, we refer to lead and table facilitators, expert leads, and project leader.
- Direct observation of deliberations over the four days.
- Direct observation of organizers' debriefing over three days.
- Documentation of jurors' testimonies in the 'diary room' – a makeshift studio filmmakers put together for jurors to reflect on their deliberative experience. Some of these testimonies will be used in a short film on the citizens' jury.
- Interviews with expert speakers to understand their take on the jury.

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<sup>1</sup> John Parkinson and Jane Mansbridge Eds. (2012), *Deliberative Systems: Deliberative Democracy at the Large Scale*, Cambridge University Press, Cambridge.

<sup>2</sup> We only collected data during the citizens' jury. This means we did not evaluate the discussions in the oversight group that informed the design of the jury as well as the process of writing the citizens' jury report.

## Positionality of evaluators

We volunteered to evaluate the citizens’ jury because of our academic interest in deliberative democracy, particularly on issues of inclusiveness, legitimacy, and integrity. Curato is one of the lead investigators of the Global Citizens’ Assembly on Genome Editing and has an interest in comparing the experiences of the Australian and UK Jury and documenting lessons for the Global Assembly. Parry, meanwhile, is one of the lead researchers (with Curato) of the Deliberative Integrity Project, which investigates the ethical conduct of deliberative mini-publics. Van Dijk is a PhD student whose work focuses on the legitimacy of deliberative mini-publics. As independent evaluators, we had no role and influence in process design and the write-up of the report.

**Table 1: Summary of data sources**

Data	Internal quality	External quality	Deliberative integrity
Evaluation questionnaires from jurors, facilitators, and organisers			
Direct observation of plenary sessions, small group deliberations, the ‘diary room’ and debriefing sessions among organisers			
Short interviews with experts and filmmakers			

# INTERNAL QUALITY

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## Key points

- The citizens' jury uncovered the diverse perspectives of the patient community.
- Diversity within a group does not necessarily mean equality within a group.
- Facilitators served as mediators to amplify underrepresented voices.
- The citizens' jury was an emotionally demanding experience.

Internal quality refers to the extent to which the principles of inclusiveness and deliberativeness were upheld in the design and implementation of the citizens' jury.

Did the jurors feel they have been able to contribute effectively during deliberations? To what extent did expert testimonies shape their views? Was the programme too fast, too slow, or just right? Did some voices dominate over others? If some voices dominated, how did facilitators respond? Whose voices were not in the room?

Our data resulted in rich insights about the internal quality of the citizens' jury. We have four key findings.

## The citizens' jury uncovered the diverse perspectives of the patient community

Citizens' juries are typically composed of a random selection of citizens to represent a microcosm of society. This jury was different. 21 jurors were recruited through Genetic Alliance UK's network of patient communities including patients, family members, and carriers of genetic conditions (see Box 1: the recruitment process).

The rationale for this recruitment strategy was to determine whether there is a 'patient push' to change the law. Given the current legal and regulatory landscape, this group will likely be the first and only group to be offered human embryo editing in the UK, if it were legalised. As project leader Professor Anna Middleton explained in a plenary session:

Are there any circumstances where you would like the law to be changed?  
Because you would like to free up the technology for your specific condition?  
So, we're not talking about enhancements. We're not talking about frivolous reasons. We're talking about the various serious, meaningful reasons that actually only you can answer ... this is a question really, for patients (Professor Anna Middleton, Wellcome Connecting Science, Day 3).

For Sophie Peet of Genetic Alliance UK, the citizens' jury was an opportunity to develop a 'loud and firm voice' so the patient community can be heard. The voice of the rare disease community is often 'drowned

out by the general public', and so the jury was a unique moment for patient groups to 'hash out the grey areas' and develop a collective position.

Indeed, 'having skin in the game' was a phrase we often heard in deliberations and in informal conversations among jurors, to explain their motivations for taking part.

### ***Box 1: Recruitment Process***

1. Genetic Alliance UK issued an open call to their networks to take part in the jury.
2. About 100 eligible applicants responded to the open call.
3. Organisers sifted through the applications. Considerations for recruitment included:
  - A broad selection of different types and inheritance patterns of genetic condition.
  - Different geography across the UK, spread of ages, ethnicities, and educational background.
  - A reflection of the ratio of men to women who come to a genetics clinic. More women than men do, so the jury had more women than men.
4. 24 jurors were initially selected and 21 participated. Three jurors did not make it in the end due to their conditions. There were no drop-outs during the process.

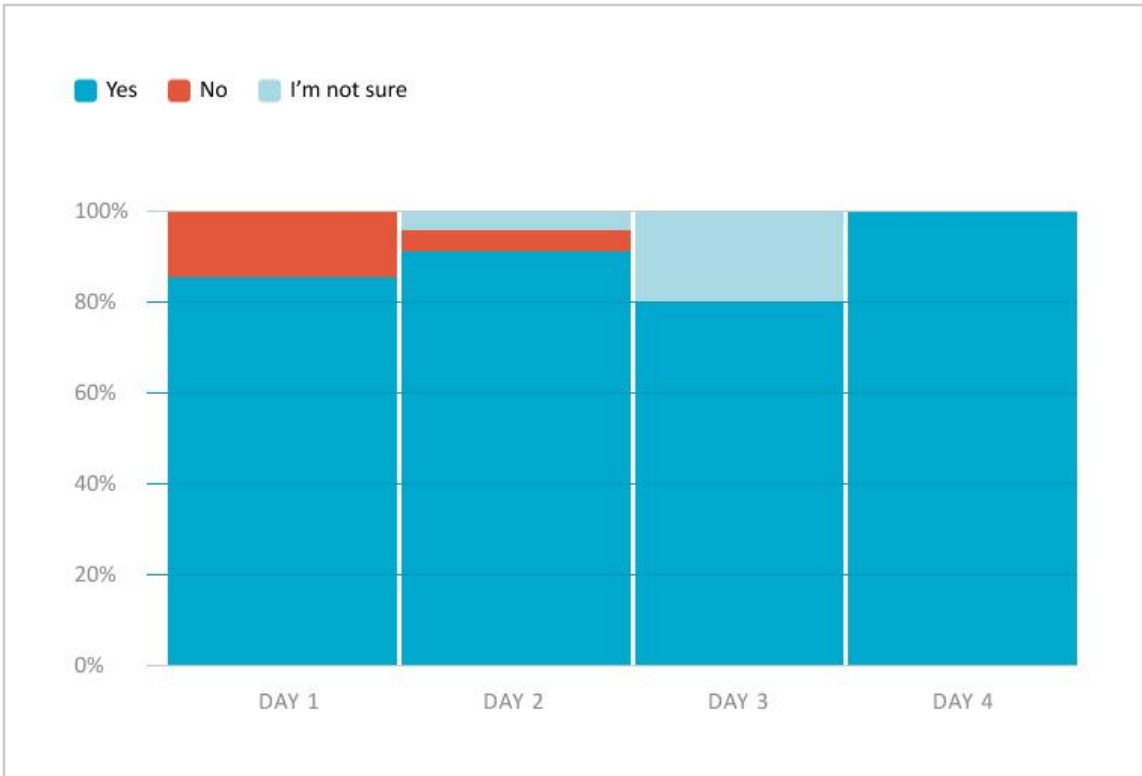
This recruitment strategy had two main consequences.

First, limiting the participants to the patient community created a supportive atmosphere. For many, disclosing their genetic condition or their experience caring for someone with a rare genetic condition happened immediately, as a way of introducing themselves and what brought them to the Wellcome Genome Campus. Everyone shared a baseline understanding of what it means to live with or care for someone with a rare genetic condition.

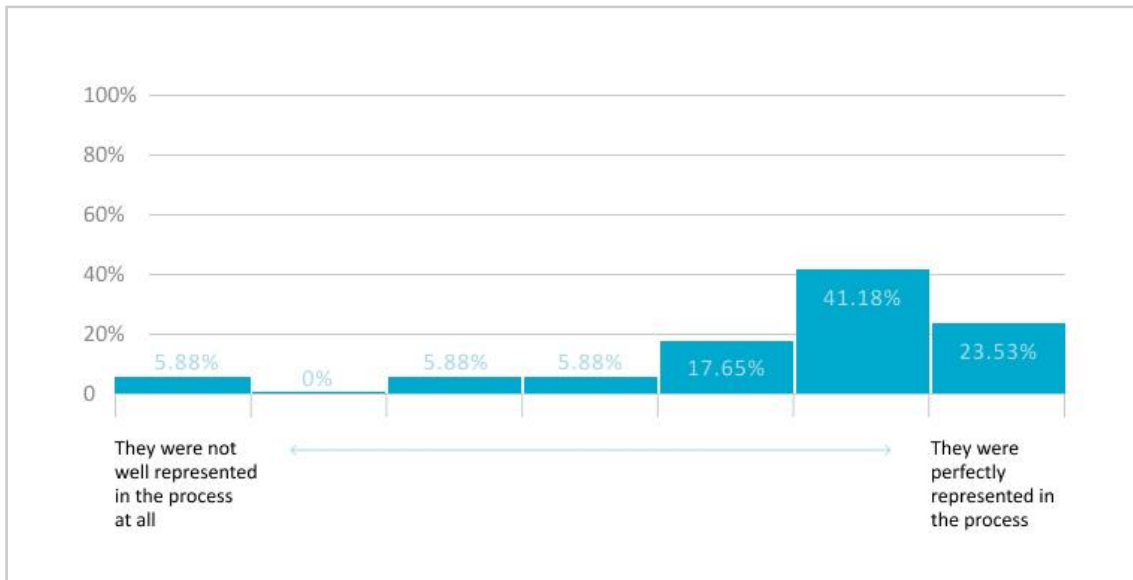
Second, jurors found the composition of the jury a positive experience, with most participants feeling they were able to effectively contribute to the deliberations with their lived experience. Some jurors highlighted the value of having a space to discuss 'topics that matter to me most' in a 'safe environment'.

The composition of the jury revealed the diversity of the patient community's experience. It is 'not as common to talk in depth to others with lived experience', said one juror in the diary room, when they were asked what part of the process was most enlightening or engaging. Many said they encountered perspectives they had not previously considered while others felt that hearing the personal stories of their fellow jurors prompted them to reconsider their views.

**Figure 1: Do you feel that you have been able to contribute effectively during today's session?**

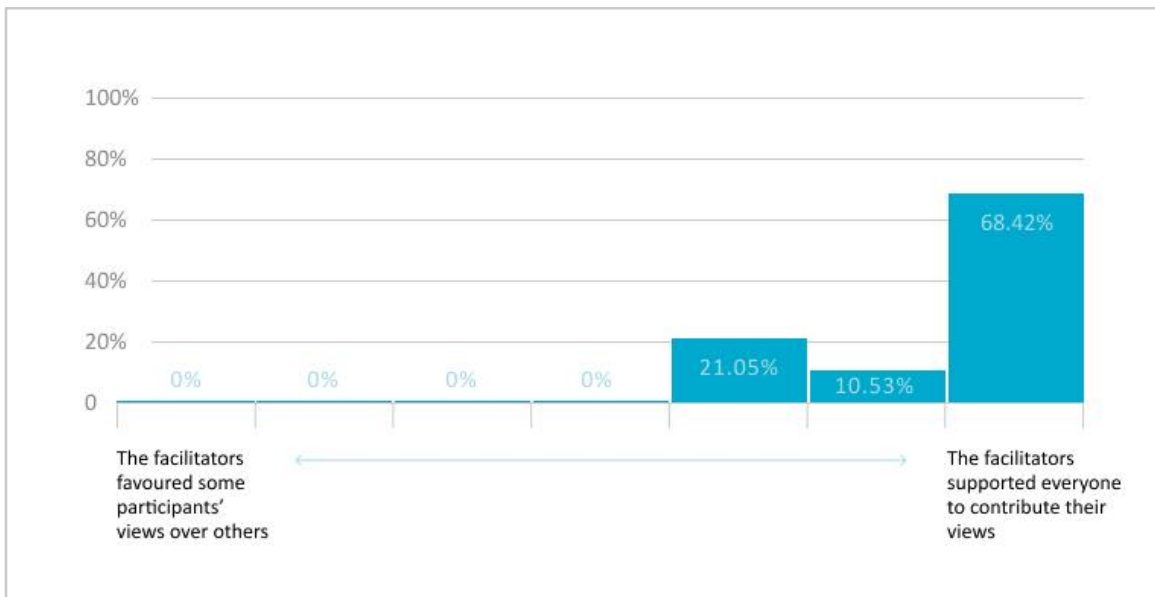


**Figure 2: How well represented were the voices of those whose lives are most affected by genetic conditions?**



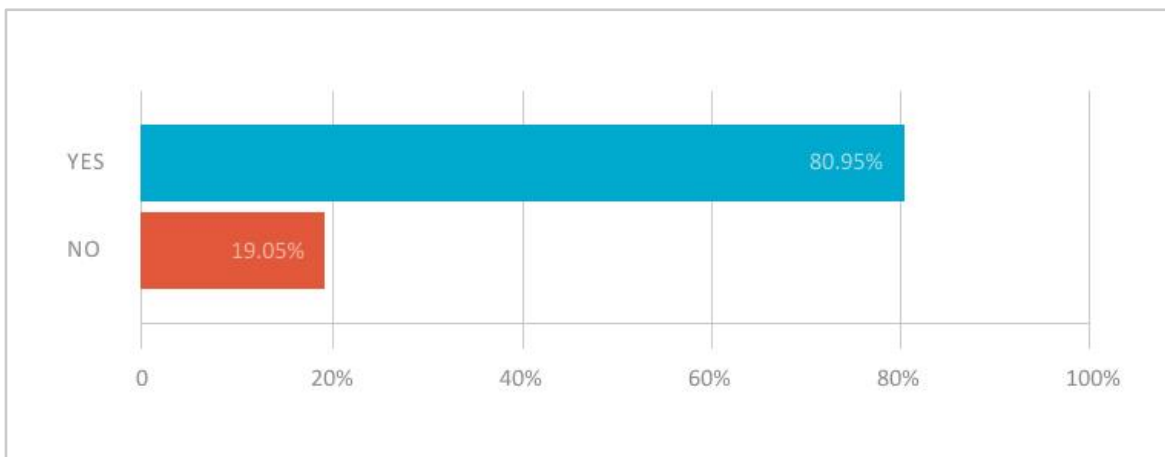
*N = 17; I'm not sure = 3.*

**Figure 3: To what extent did you feel that the facilitators supported everyone to contribute their views?**



*N = 19; I'm not sure = 1.*

**Figure 4: Did the fellow jurors make you reconsider your views?**



*N = 21.*

## Diversity, however, does not mean equality

To have diverse voices and experiences in the room did not mean that all voices were equally represented in the room. In our evaluation questionnaire, we asked jurors to reflect on voices that were not well represented, which is a standard question for evaluations on citizens' juries. One felt that the voices of parents who are asymptomatic carriers of genetic conditions were overrepresented, while another felt that those who are living with genetic conditions or 'visibly disabled' were 'not adequately represented'. 'I think more rare disease people should have [been] included than carriers, [e]specially asymptomatic carriers', as one juror put it. Others wanted to hear from 'people who are visibly disabled as a child' and 'those with intellectual disabilities'.

Given the perceived absence of some perspectives, several jurors felt a responsibility for speaking for those who they thought were not in the room. One felt she had to represent the experience of their child who had passed away, while others felt that they could not excuse themselves from deliberations for a break as they might miss an opportunity to voice their underrepresented concerns to the wider group.

Information about the specific conditions of each jury member, or the proportion of people living with a serious genetic condition, was not disclosed to the jury or to evaluators, to protect confidentiality. It was thus jurors' choice whether or not to disclose their condition to others, and some did not. Therefore, the jury's perceptions around who was or was not well represented in the room was based on partial information, and thus some potentially mistaken assumptions about the proportion of people living with symptomatic genetic conditions.

Relatedly, we observed that some individuals who are already marginalised in broader society also felt marginalised during the jury. 'A lot of people here are coming from privilege and that has affected the outcome of the process,' one participant wrote on a sticky note handed to the evaluation team at the end of the jury. 'Representation doesn't necessarily mean inclusion,' the participant wrote. 'Future events should include and accountably look into ensuring inclusion of minority voices, particularly from racialized backgrounds,' they added. One organiser affirmed this observation in the evaluation form, stating that 'jurors from White British backgrounds' were 'more represented than others, thus reproducing specific forms of injustices.'

We noted instances when jurors from ethnic minority communities tried to advance arguments that foregrounded issues of structural inequality, such as unequal access to healthcare and differential health outcomes. This concern, however, did not gain much traction in table deliberations. Some participants sought ways to keep this issue alive. It was noticeable that jurors from ethnic minority backgrounds gravitated to the theme of 'diversity, equity, and inclusion' in the open space, with only one white person joining the group. We also observed one juror putting blue sticky notes on each recommendation written on flipcharts that failed to consider issues of diversity, with the word 'diversity' serving as a more palatable catchphrase for inequities. In one open space table discussion, some jurors pointed out to the whole group that the topic of 'diversity, equity, and inclusion' should not be considered a separate theme but should be considered an underlying and cross-cutting principle for all recommendations being developed. When jurors finalised their recommendations, they agreed that this should be the case and it should be included in all the recommendations.

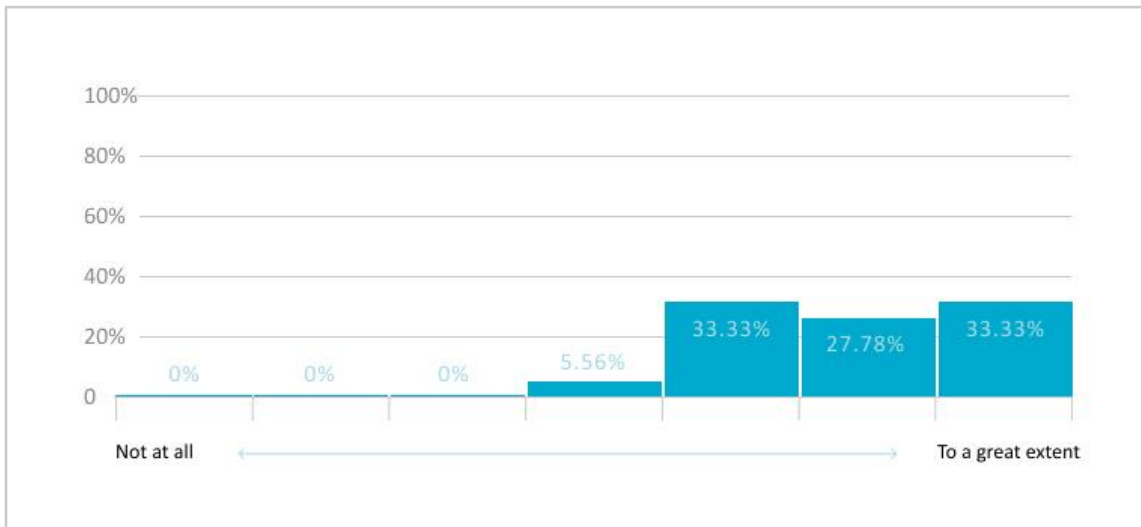
Organisers made an effort to over-recruit minority voices. It was these participants who were ultimately unable to attend the jury due to their condition. This meant that the final jury composition was visibly



weighted towards people from a White British background. This background information was not shared with the jurors.

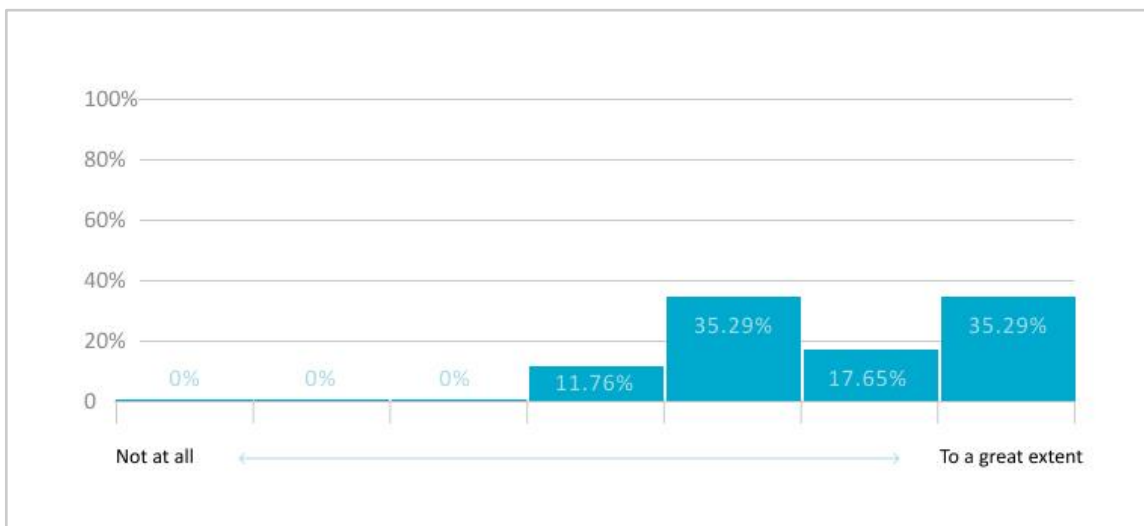
These issues highlight a dilemma relevant to this specific jury – maintaining a balance between transparency and confidentiality. On the one hand, without the full picture about genetic conditions and the recruitment process, jurors questioned the extent to which patient voices were well represented and what the implications were. On the other hand, the need to protect jurors’ privacy and wishes is obvious, especially with a small group where people are more easily identifiable.

**Figure 5: I received sufficient information from the speakers to contribute to the deliberations**



*N = 18; I'm not sure = 0.*

**Figure 6: I found the information booklet helpful in deliberations**



*N = 17; I'm not sure = 1.*

## Facilitators served as mediators to amplify underrepresented voices

Arguments about structural inequality received fair hearing among table facilitators. Much of the feedback about inequalities playing out in deliberations were not overtly expressed in the jury room, but in the ‘diary room’ and in one-on-one conversations with facilitators.

Facilitators, in turn, carried these discussions into the debriefing sessions. At the end of each day, the organisers took stock of what worked and what needed improvement and agreed on design adjustments to address issues raised. In one debriefing, a facilitator shared their observation that a juror from an ethnic minority background felt the burden of carrying the argument on structural inequalities, and it would be helpful if one of the experts amplified this argument in a plenary session. Expert lead Sasha Henriques and Professor Anna Middleton then raised these issues in the plenary session the following day.

Aside from raising issues of racial inequalities, facilitators looked out for younger jurors who were less active in table deliberations. Facilitators decided to pair young jurors together in table deliberations as they appeared to be more comfortable expressing their views in one-on-one conversations with jurors their age than in the whole group discussions. Other facilitators found techniques to encourage less active jurors to speak. One facilitator, for example, suggested to a juror to give her a signal if the juror wanted to speak but found it challenging to insert her voice in on-going deliberations.

Finally, facilitators provided assessments on the energy and engagement levels around the tables. One facilitator observed that the pace of the process was ‘pretty unforgiving’ for jurors who needed additional time to process things – either due to their condition or emotional state. Jurors who were having a challenging day were sometimes subsequently less engaged in discussion. In response to this, facilitators suggested that more ‘buffer time’ should be built into the schedule – time and space to process information and discussions. This suggestion was initially planned to be taken up by organisers but wasn’t in the end due to time constraints (see section 8.3).

Our observations demonstrate that facilitators are not always neutral actors in a citizens’ jury but can serve as advocates for jurors by amplifying silenced voices and caring for jurors’ wellbeing.<sup>3</sup>

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<sup>3</sup> See Oliver Escobar (2019). Facilitators: the micropolitics of public participation and deliberation. In Stephen Elstub and Oliver Escobar (Eds.) *Handbook of Democratic Innovation and Governance* (pp. 178-195). Edward Elgar Publishing.

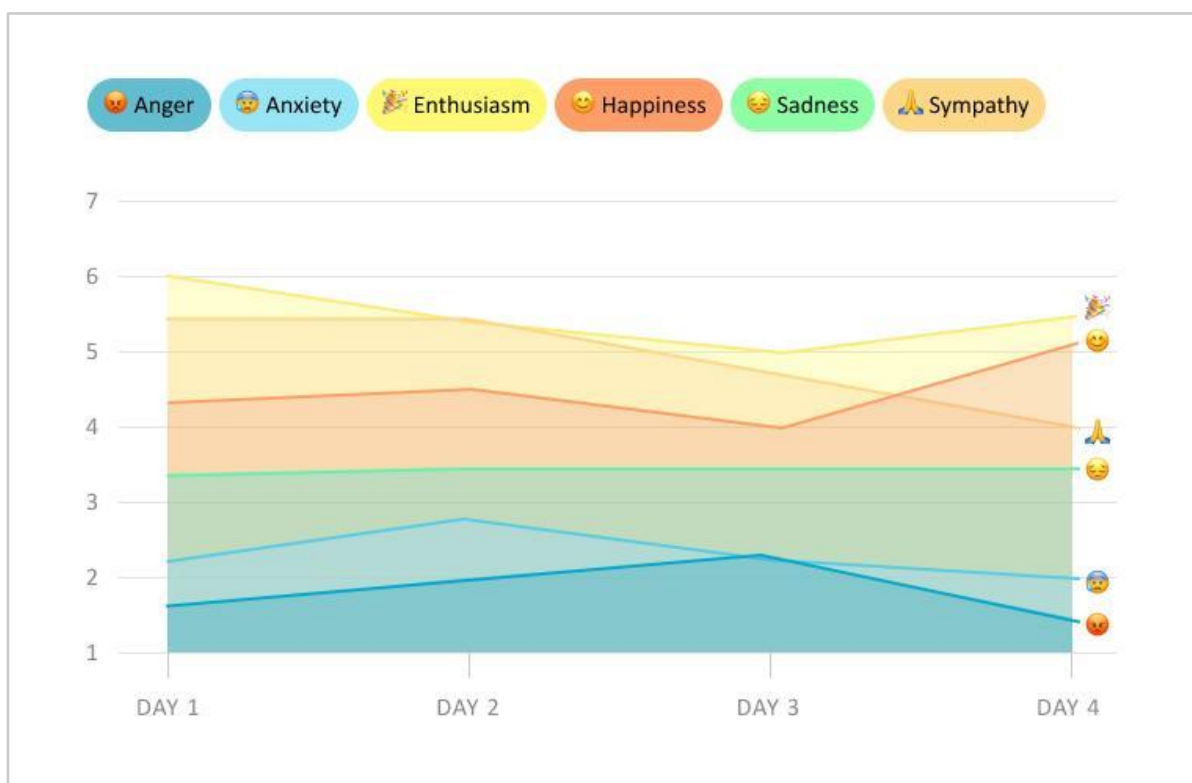
## The citizens' jury was an emotionally demanding experience

Having a participant group with lived experiences of rare genetic conditions meant that high emotionality was an inevitable part of the jury. On several occasions, we observed jurors crying or trying to hold back tears. This came across in plenary sessions where jurors reflected on their own experiences. In a discussion over the definition of a 'serious condition', one juror acknowledged that their condition would come under the current definition and that they might have a reduced lifespan. They asked the room, 'does that seriousness reduce the value of my life? I don't think it does.' Another commented that after the first two days of the jury, they realised that a change in the law would be unlikely to happen in time to help their family, which was a weighty realisation.

'It is difficult not to feel emotional about issues which directly impact your family,' one juror said in the evaluation form. 'Hearing people's difficult experiences made me feel sad and sympathy,' said another.

We tracked jurors' emotions over four days as a way of checking their well-being. It is noticeable that the third day was an emotionally challenging time, as anger peaked while happiness and enthusiasm declined. There were various reasons for this, although two themes were resonant in our questionnaire.

Figure 7: Sentiment Tracker<sup>4</sup>



<sup>4</sup> Method inspired by: Genevieve Fuji Johnson, Michael Morrell, & Laura Black (2019). Emotions and deliberation in the Citizens' Initiative Review. *Social Science Quarterly*, 100(6), 2168-2187.

First, some participants felt the day was quite ‘heavy’ as jurors had to discuss what it meant to have a ‘serious’ condition. Part of these deliberations were stories from jurors who had lost their loved ones from a genetic disease.

Second, some participants became less enthusiastic about the jury after feeling that their views were being sidelined. One juror felt ‘silenced’ after her suggestion that issues of diversity, equity, and inclusion should be the foundation of all recommendations, and not a separate theme. Another felt that there was little understanding of the ‘suffering’ of people with rare diseases and they felt frustration about that.

Two genetic counsellors were present to support participants in an emotionally charged citizens’ jury. These counsellors also played the roles of project lead (Middleton) and expert lead (Henriques). They reiterated their availability for counselling as the jury went on and some jurors did approach them as deliberations unfolded, taking time out from the process to speak with them. It is worth noting that the intentional availability of genetic counselling, delivered by master’s level trained counsellors, goes beyond what would routinely be offered in terms of support to genetics patients in an engagement or policy event, outside of a clinical setting. The offer of this demonstrates that thought and consideration had been given to the specific circumstances related to being a genetics patient.

In one debriefing session, the organisers pointed out that they expected this ‘storm of emotions’ and that this is the daily reality in their work as genetic counsellors. The organisers were ready for this, hence the appointment of two genetic counsellors available for all jurors to speak to at any point in the jury.

### *Points for Reflection*

- Does a citizens’ jury necessarily subsume issues of racialized disadvantage as one of many diverse perspectives and issues to be considered in deliberations? To what extent can a citizens’ jury foreground issues of equity?
- What kind of preparation do jurors, organisers, facilitators, and filmmakers need to adequately deal with an emotionally challenging topic?
- How can citizens’ juries be more cognisant of seemingly mundane but nevertheless serious barriers to full participation such as physical and emotional fatigue?

# EXTERNAL QUALITY

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## Key points

- Jurors and expert speakers have a measured expectation about the citizens' jury's impact.
- Experts find that jury recommendations offer a distinct input into policymaking.
- Filming the citizens' jury has the potential to spark a wider conversation about genome editing.

The citizens' jury was a public engagement activity of Wellcome Connecting Science. It was held to generate the patient community's input into policymaking and shape conversations within the wider society. It was not commissioned by decision-making bodies like regulatory agencies or Parliament, and so a direct response from decision-makers was not expected.

Aside from producing a final report that can inform policymaking, a short film will be released to amplify the process and outcome of the jury to the wider public.

To assess the external quality of the citizens' jury, we examined the various ways in which the jurors, organisers, filmmakers, and experts interpreted how the outcome of the jury will connect to decision-making and the wider public. We have three main findings.

## Jurors and expert speakers have a measured expectation about the citizens' jury's impact

In our final questionnaire, we asked jurors to complete these sentences:

- Ideally, I hope that the recommendations of the Citizens' Jury will ...
- In reality, I think that the recommendations of the Citizens' Jury will ...

In terms of ideal outcomes, some jurors hoped that their recommendations would be directly implemented by Parliament while others saw their contribution as an input to policymaking. For some, the outcomes of the jury could trigger a wider conversation.

**Table 2: Ideal outcomes**

<b>Adapted into law</b>	<b>Influence policymaking</b>	<b>Start a wider conversation</b>
<p>‘Acted on quickly and be seen in parliament soon.’</p> <p>‘Be implemented and the government allows genetic editing of embryos to start.’</p> <p>‘A change in policy for allowing gene editing to people like me suffering with extreme rare diseases.’</p>	<p>‘Be considered by policymakers.’</p> <p>‘Make those with power and influence consider addressing issues currently facing society before approving gene editing.’</p> <p>‘Be sufficiently clear and robust to influence policymakers.’</p>	<p>‘Open up the lid on this subject and shine a light on the situation as it had been dormant for so long.’</p> <p>‘Help set the ball going.’</p> <p>‘Allow an informed and balanced discussion to be possible’</p>

Source: Day 4 evaluation questionnaire (select responses)

When prompted to think about the realistic impact of their recommendations, jurors expressed a more measured expectation. Most thought that their recommendations will only be one component of a wider conversation, while others saw the jury as one part of the broader policymaking process. Others expressed a sceptical take as they recognised the wider political context in which the law will be debated.

**Table 3: Realistic expected outcomes**

<b>Become part of the policy process</b>	<b>Start a wider conversation</b>	<b>Limited or negative outcome</b>
<p>‘Help support the process where the government seeks input from interested parties to help formulate a change in policy.’</p> <p>‘Only be part of a big process that may have other more powerful drivers beyond our control.’</p> <p>‘Be taken into consideration by the HFEA, scientific advisory committees and policymakers.’</p>	<p>‘Bring the conversation into the public domain.’</p> <p>‘Open discussion, open minds, and start consideration and options for future.’</p> <p>‘Be a good starting point for future deliberations, consultations, and actions.’</p>	<p>‘Be of interest to those involved + the scientific community but may not be taken seriously by policymakers.’</p> <p>‘Be manipulated and twisted to fulfil selfish aims.’</p> <p>‘Be taken partially into account when considering the change in law and have no impact on wider processes/services.’</p>

Source: Day 4 evaluation questionnaire (select responses)

A few jurors felt disappointed as they learned about the complexity of the science, ethics, and policy on genome editing. They realised that participating in the jury would be unlikely to directly help them or their family.

An expert speaker considers the citizens' jury as 'part of a jigsaw.' They explained that:

'The reality check [is that] now is not the right time. This is not going to have an immediate impact on things...maybe it will have to be something that we will visit in a few years' time, in a different political context. There's so much going on there politically, that I think this will have very little direct impact now, because I think the government priorities have been stalled, there are things that ministers now have a different personal perspective on [this], from what we hear (Expert speaker, interview).

That said, they also indicated that 'things could change quite quickly'. Developments around the world, including the popularity of medical tourism, could prompt the UK government to review current laws and regulations. It is in this context that the jury's recommendations could feed into policymaking.

## Experts find the recommendations of the jury offer distinct input into policymaking

While the jury's recommendations may not secure an immediate impact in policymaking, most expert speakers found a distinct value to the jury's recommendations. 'Compared to something like a survey or a questionnaire,' said scientist Oliver Bower, 'you can send it out to millions of people, but it is very superficial data and information you get from it.' A citizens' jury offers something different. It may have a narrower sample, but it offers rich information and 'a real good look at how people feel about this'. Sarah Bowdin, the Medical Director of the East Genomic Laboratory Hub, affirmed this view; the 'depth and intensity of the process' sets it. Some public engagement activities only give citizens an hour to make their mind up on an issue, but the duration and intensity of the citizens' jury gives a more nuanced view of the patient communities' perspectives.

Sarah Norcross, Director of Progress Educational Trust, also underscored the credibility of jury recommendations as its distinctive quality. Norcross observed that the jurors were 'asking great questions,' and 'they don't seem to be hijacking for a particular agenda'. That jurors seem to have kept an open mind and understood the question they had to answer, instead of just announcing their own perspectives, adds weight to the recommendations of the jury for the experts we spoke to.

## Filming the citizens' jury has the potential to spark a wider conversation about genome editing

The citizens' jury was described as 'a creative project', in the handbook distributed to all participants. The organisers commissioned Green Eyed Monster Films and Lambda Films to create a short documentary to be released on social media platforms. One of the filmmakers stated that there is a 'readymade niche

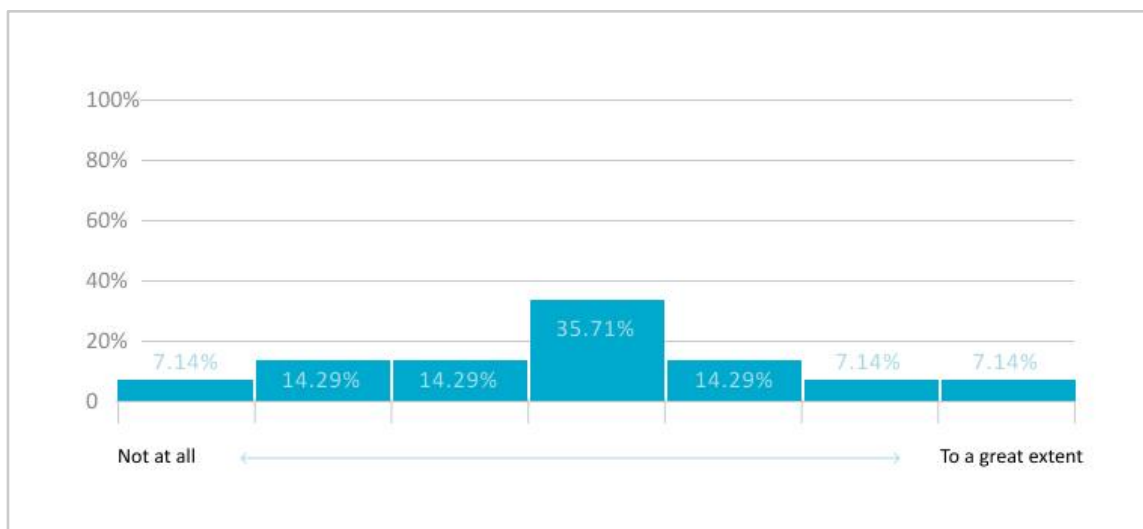
audience' for the film among people interested in genetics or citizens' juries. It may be played in conferences or screened in international film festivals.

The film 'is more likely to be more niche because it is single location', one of the filmmakers explained:

We're just based on campus here. And we're meeting people at this amazing facility. And if you're a member of the public watching this, you kind of go on well, I've never been to an amazing facility like that. So, there's distance there (Filmmaker, Interview, Day 4).

Filmmakers invited all participants to share their reflections on the on-going proceedings in a 'diary room' (so named by the jurors themselves) – a makeshift studio in a bar in Hinxton Hall, a grade 2 listed building right across from the modern conference centre which was the venue of the jury. In the diary room, we observed some jurors candidly sharing their experiences of being part of the citizens' jury. Despite being in front of camera, the jurors reflected on what they found enlightening and engaging, but also the challenges they encountered. We observed that some of the jurors appeared to share their more critical views of the process on camera rather than in the jury room itself. In our final evaluation, however, there was a spread of views when we asked jurors whether sharing their thoughts on camera with the film crew helped them reflect on the deliberations so far.

**Figure 8: Sharing my thoughts on camera with the film crew helped me to reflect on the deliberations so far**



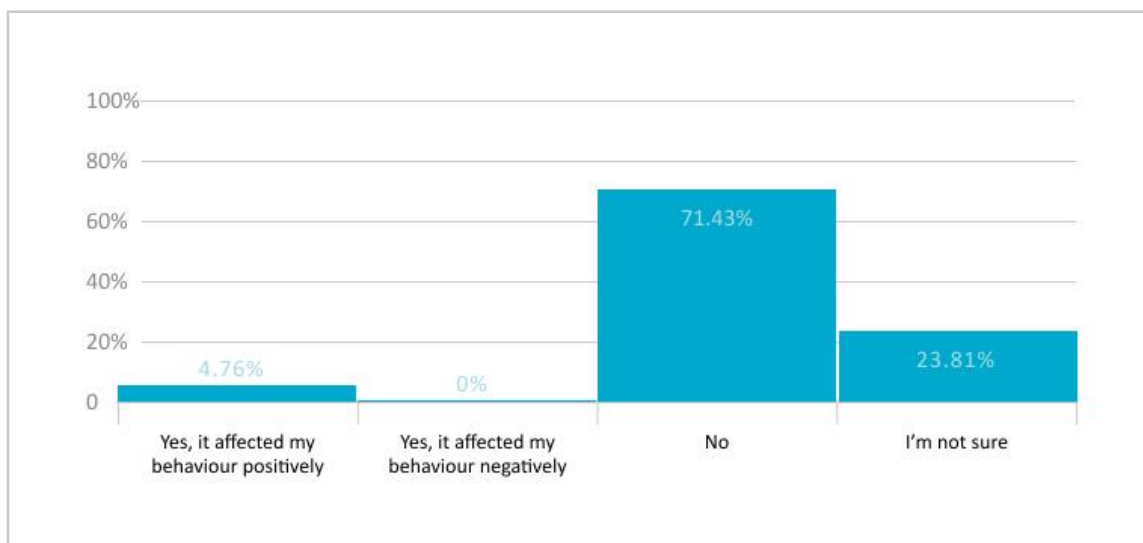
*N = 14; I'm not sure = 4.*

The jurors also took turns in wearing a microphone during deliberations as part of the film. In our Day 1 questionnaire, we asked the jurors whether the presence of cameras and microphones affected their behaviour. The majority said it did not, while a few were not sure. We asked a similar question on the final day and the majority felt that this did not stop them from speaking their minds.



This question was asked on Day 1 of the Citizens' Jury.

**Figure 9: Did the presence of recording devices (e.g. video cameras) affect your behaviour?**



*N* = 21.

Our evaluation found that the film has potential to spark wider conversations about genome editing or the jury process itself, and the presence of the film crew did not appear to negatively impact the jurors' experience. However, the impact of the film, and the audience it will attract, will be more fully understood once the film is released.

### ***Points for Reflection***

- How can the jurors' expectations about impact be managed especially when they have such high stakes on the topic?
- What is the appropriate political timing to call a citizens' jury?
- To what extent can the visual and storytelling requirements of a powerful film be reconciled with the design requirements of a citizens' jury?

# DELIBERATIVE INTEGRITY

## Key points

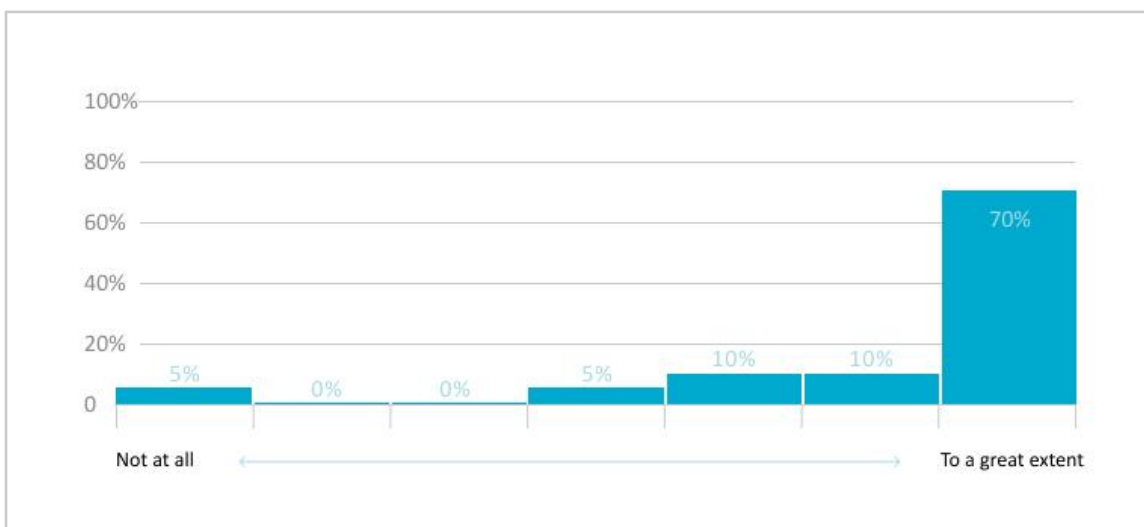
- Responsiveness was the organisers' key integrity practice.
- Speakers played the role of 'conversation partners,' not 'all-knowing experts' who imposed their views on the jurors.
- Time was one of the main pressure points.
- Debriefing sessions were an open space for reflexive practice.

The last part of our evaluation examined how the citizens' jury was governed. We wanted to know whether the process upheld principles of ethical conduct. We also monitored whether experts, organisers, facilitators, or other parties wielded disproportionate influence in deliberations.

The data we collected demonstrated that the citizens' jury conforms to norms of deliberative integrity and ethical conduct. The jurors found the process to be fair. They understood the purpose of the jury, who commissioned it, and the roles of people involved in running the process. The jurors felt that the organisers were genuinely interested in their views. Most think the remit asked the right question.

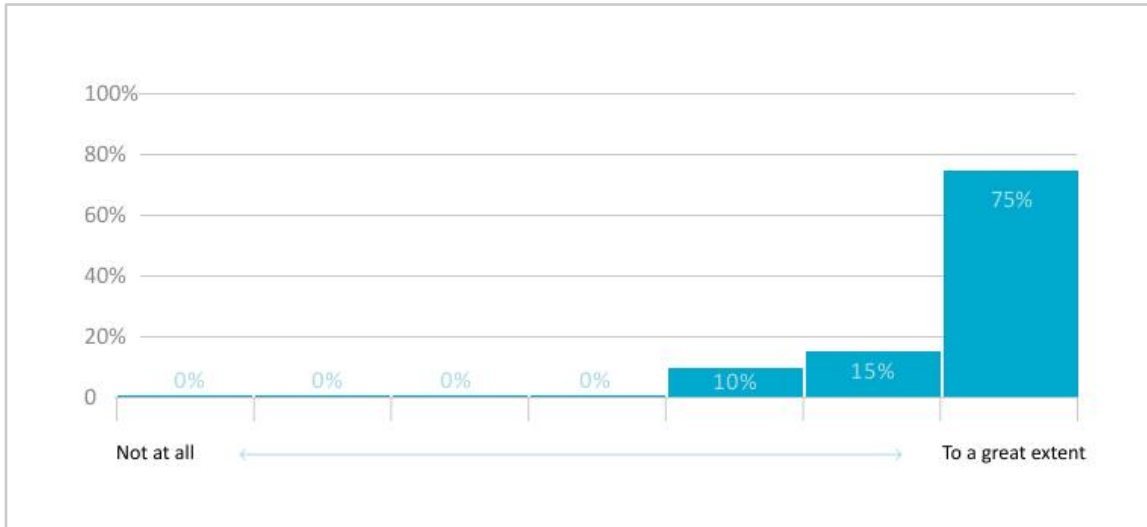
The handbook distributed to participants provided the qualifications of expert speakers, identified specific contact persons to address the jurors' needs, and identified project partners involved in the event. The organisers also put together an oversight group to provide input on the remit, the selection of experts and process design to check for issues of bias. All participants – jurors, experts, organisers, facilitators, and the evaluation team – were given consent forms ahead of time.

**Figure 10: The process of the Citizens' Jury was fair**



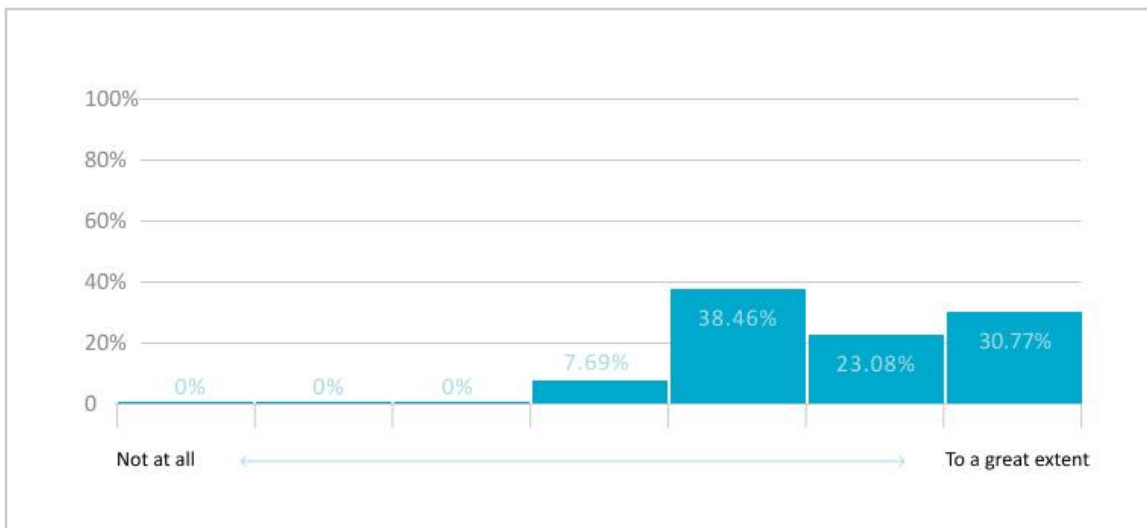
*N = 20; I'm not sure = 0.*

**Figure 11: I understood the purpose of the Citizens' Jury**



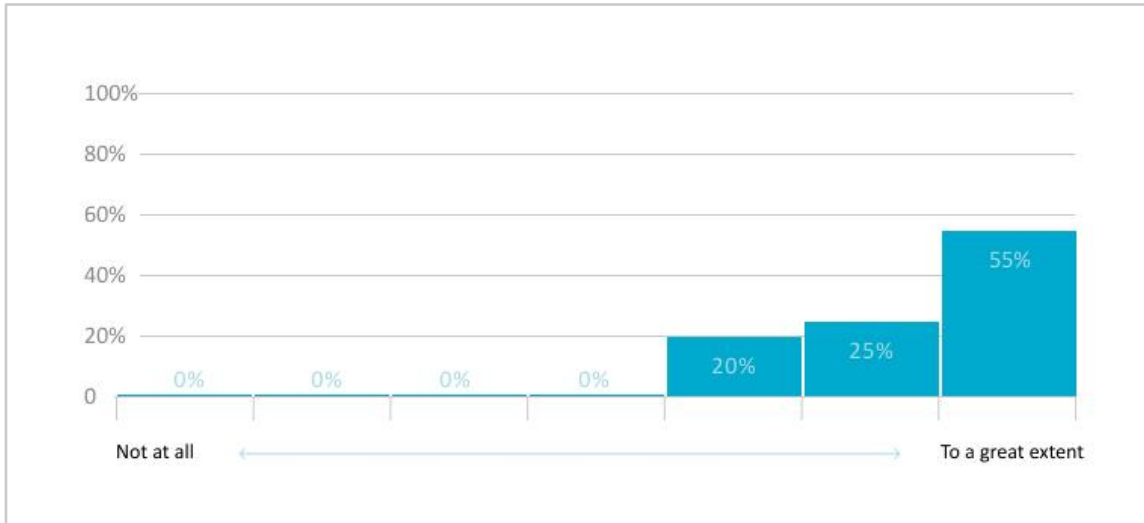
*N = 20; I'm not sure = 0.*

**Figure 12: The question given to the jury to answer was the right question**



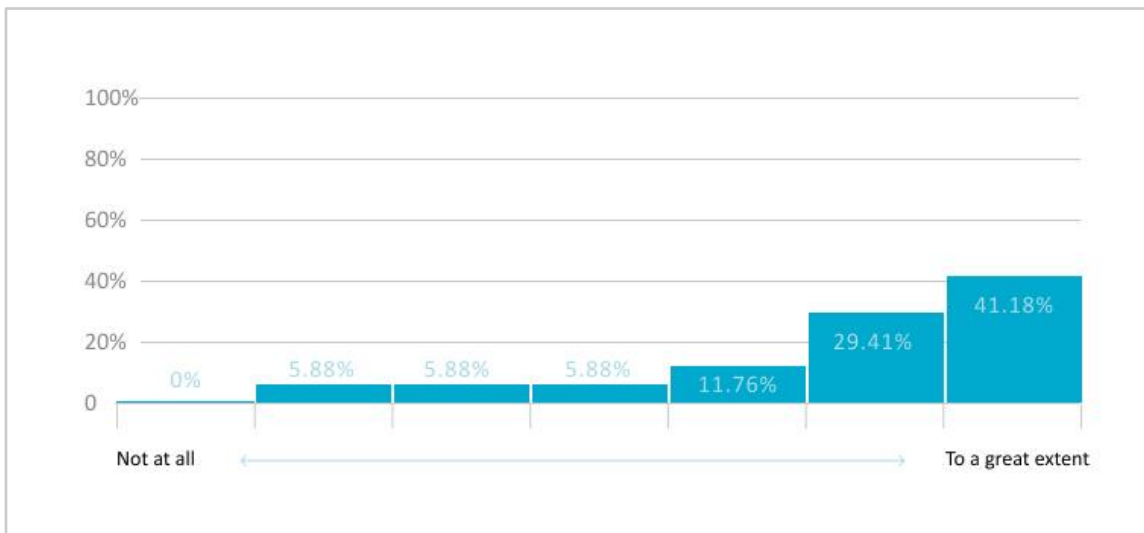
*N = 13; I'm not sure = 3.*

**Figure 13: I understood the roles of different people involved in the process**



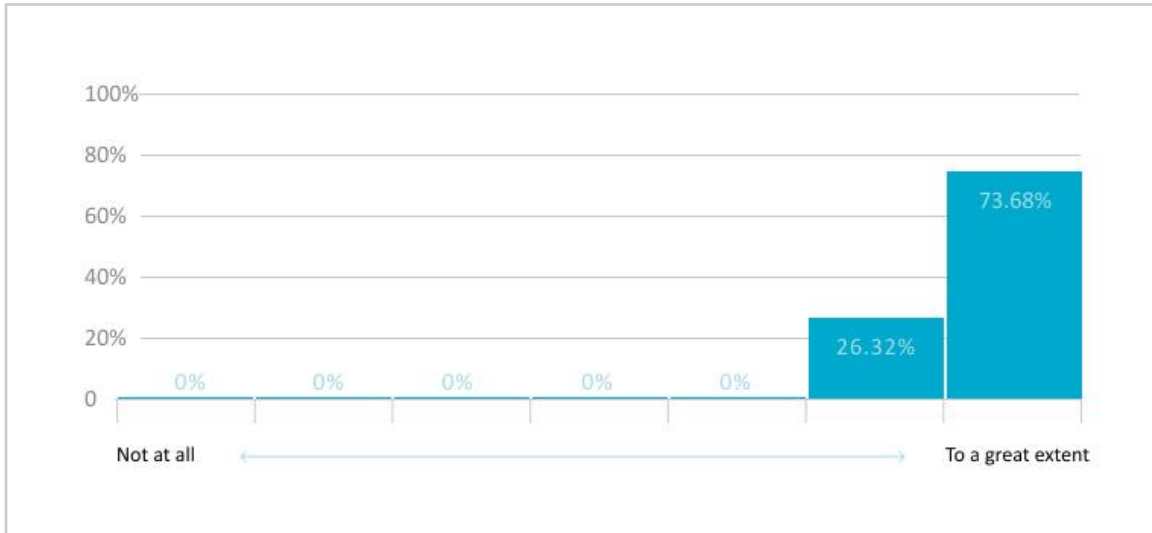
*N = 20; I'm not sure = 0.*

**Figure 14: I know who commissioned the Citizens' Jury and why**



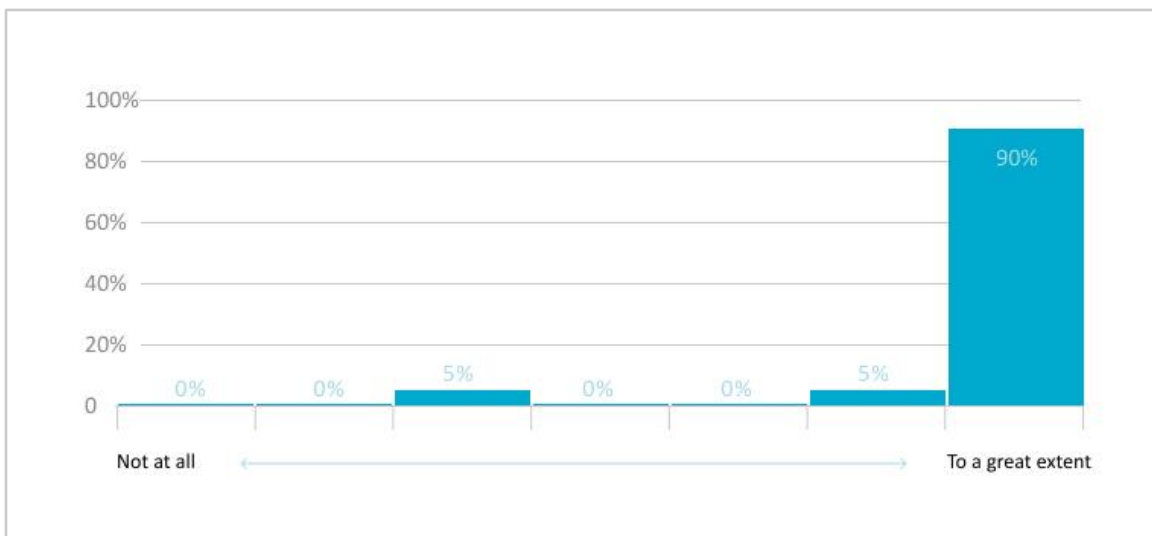
*N = 17; I'm not sure = 0.*

**Figure 15: I think the people who organised the Citizens' Jury are genuinely interested in my views**



*N = 19; I'm not sure = 1.*

**Figure 16: I think this Citizens' Jury was a good use of my time**



*N = 20; I'm not sure = 0.*

We have four key observations on deliberative integrity.

## Responsiveness was the organisers' key integrity practice

We observed that responsiveness was the most prominent integrity practice upheld by the organisers. As issues were raised by either jurors, facilitators or evaluators, organisers sought to respond to them. For example, we observed that organisers did not disclose all the organisational details of the citizens' jury to participants upfront. How the jurors or experts were selected, who comprised the oversight group, the thinking behind the remit, the rationale for distributing jurors in various tables were not discussed in the briefing with the jurors on the first day.

As a result, the jurors took it upon themselves to seek clarification about various aspects of the jury. Some jurors queried whether the wording of the remit skewed the vote to yes, given that the remit was so cautiously worded ('are there *any circumstances* under which the UK Government should *consider* changing the law ...'). There was some discussion over this wording, including the distinction between 'circumstances' and 'conditions' under which the law should be changed. This allowed jurors to bring in concerns relevant to them that were outside the immediate remit, such as developing a set of conditions that should be in place for any change in the law to happen. These conditions or principles covered topics such as equity and access to healthcare and genetic services.

Jurors also asked for more information about how and why they were selected. The absence of this information from the beginning sparked conversations about the representativeness of their group, whether they were tasked to represent the wider patient community, or whether they should only speak for themselves. Some jurors felt the pressure to be 'objective' instead of speaking from their experience. This was clarified on Day 3, when organisers explained the rationale behind the recruitment process, including the gender balance in the group (more female than male) which was intentional to reflect the population of people who attend clinical genetics clinics. Organisers also emphasised throughout that jurors bore no burden of representing anyone other than themselves and their experiences.

As evaluators, we created a mechanism to convey jurors' concerns to the organisers and support responsiveness. Each day, we asked the jurors in their evaluation forms to state improvements for the following day. We also checked if they had requested additional support if it had been provided. Most jurors considered organisers to be responsive to their needs.

Organisers and lead facilitators were also responsive to concerns expressed by facilitators during the daily debriefs. For example, it was picked up that there was some confusion over the wording of the question, and Prof Anna Middleton then addressed this the following day. The planned vote for the question was a binary yes/no; this was changed to the 0-10 scale after its potentially polarising effect was discussed in a debriefing. Likewise, after facilitators expressed their concern about structural inequalities in the room, this was raised in the plenary the next morning and the existence of structural inequalities was acknowledged as both a fact and broader context of the discussion.

Not all requests from facilitators received the same degree of responsiveness. Requests for additional 'buffer time' and time spent outside of the jury room for jurors to reconnect with each other were considered. After further consideration by lead facilitators, it was decided that this request also needed to

be weighed in relation to the commitment made to jurors that they will be given enough time to produce recommendations.

**Table 4: If you asked for any additional information or support yesterday, have the organisers responded to your request?**

	Day 2	Day 3
Yes, I have received a response that I consider adequate	23.3% (n=4)	21.1% (n=4)
Yes, I have received a response, but it was not adequate	0.0% (n=0)	0.0% (n=0)
I have not asked for any additional information or support	70.6% (n=12)	68.4% (n=13)
No, I have not received a response	0.0% (n=0)	10.5% (n=5)
I'm not sure	5.9% (n=1)	0.0% (n=0)

## Speakers played the role of ‘conversation partners,’ not ‘all-knowing experts’ who imposed their views on the jurors

‘The experts are not here to provide the answers, but to show why these issues are not settled yet.’ This was how the organisers framed the role of expert speakers in the citizens’ jury.

The design of the jury’s learning phase affirmed this framing. Expert speakers were each given seven to eight minutes to talk about the topic assigned to them. The style of delivery was designed to be informal, with no PowerPoint slides. Handouts were occasionally given to jurors when the explanation demanded visual representation. It was ‘a bit of a challenge to squeeze some information into about eight minutes,’ said one expert, ‘but otherwise I did like the format. The format was conversational, and it did feel I was able to communicate effectively,’ the expert added. Another expert appreciated the ‘ban’ on PowerPoint slides. ‘Not having done a PowerPoint presentation probably saved everybody from me standing and staring at the screen,’ said one expert. ‘You have to engage with the audience a bit more.’

Although experts only had a few minutes to discuss their topic, they were given time to go around tables and directly engage with the jurors. This approach reinforced the identity of speakers not as all-knowing experts but as conversation partners. Some experts felt this approach set the jury apart from their previous experience in public engagement. As one expert put it:

There's a lot of situations in public engagement where you're sort of on a pedestal for it, and you're disconnected from it. Whereas something like this, I mean, I give a talk in a conversational format, like, no slides... I go around to each individual table and I can have individual questions from people on specific issues ... and I think it helps their understanding. It helps build that trust. And I think that's something I really like about the process. It's very democratic. (Expert speaker, interview).

In our daily surveys, jurors also appreciated this format and the opportunity 'to ask questions in a more relaxed setting'. Most jurors felt that they received sufficient information from the expert speakers to inform their deliberations. In the final survey, it was mainly arguments based on scientific evidence and arguments based on personal stories that prompted them reconsider their views.

As mentioned in the section on internal quality, some jurors wanted to hear from experts who could speak to issues of health inequalities, while others wanted to hear from religious experts outside the Islamic and Christian traditions. The jurors were not given the power to call in new expert witnesses, but they had the power to ask expert leads and organisers to convey their questions to speakers who were not in the room and receive answers to their queries the following day. Some jurors expressed preference for experts to be physically present in the room, instead of providing pre-recorded testimonies, so they could engage directly with them in small group deliberations and breaks. Expert lead Sasha Henriques stood in for experts who were not present in the room during the Q&A, although it was clarified that she was speaking based on her own expertise, and not on behalf of speakers who were not present.

**Table 5: Specialisations of expert speakers**

<b>Name of speaker</b>	<b>Topic</b>	<b>Format</b>
Sasha Henriques	The science of heritable diseases	In person
Oliver Bower	An introduction to DNA, genes and genome editing	In person
Sarah Norcross	The legal and policy context	In person
Dr Felicity Boardman	The ethical and social context	In person
Dr Mark Sheehan	Application in a research setting	In person
Dr Sarah Bowdin	Potential application in a clinical setting	In person
Dr Mark Sheehan	What are we waiting for?	In person
Prof Jackie Leach Scully	We should wait	Recorded (based in Australia)
Sarah Norcross	Sort out the practicalities first	In person



Dr Sarah Bowdin	A clinical perspective on the realism of genome editing	In person
Sara Levene	A view from the private sector	Recorded
Esther Fox	Thoughts on what a 'patient' perspective might be	Recorded (precaution against Covid)
Trevor Stammers	A Christian perspective	In person
Mufti Zubair Butts <sup>5</sup>	An Islamic perspective	Recorded (expert originally invited to present in-person caught Covid)
Oliver Bower	A research scientist's perspective	In person

## Time was the main pressure point.

Time has always been a pressure point in citizens' juries.<sup>6</sup> It was not a surprise to hear jurors describe the event as 'intense' and 'exhausting'; these are common experiences from a deliberative process that requires processing complex information over several full days.

This citizens' jury, however, was particularly unique. First, jurors have lived experiences of genetic conditions, which required time and space to process topics that were deeply personal.<sup>7</sup> Second, some jurors were dealing with conditions that made them physically uncomfortable (e.g., due to spine conditions or eyesight problems). We observed cushions passed around throughout the week as people became uncomfortable sitting for long periods, while others had to leave the room to rest. The conference venue hosting the jury were on hand to try and support jurors' needs. They provided blankets and cushions, large print signage and additional rooms and storage were available for medication and jurors with babies.

Some jurors felt fatigued, and therefore needed more breaks and time out to digest topics – an option that organisers frequently reminded them of. Others were visibly tired, and a few fell asleep at their tables. Organisers made efforts to accommodate jurors' needs. Nonetheless, a citizens' jury process requires sitting, listening, and absorbing information for extended periods of time, which are often physically, cognitively, and emotionally demanding.

While most jurors felt that the pace of the programme was appropriate, some expressed concerns about feeling rushed. 'I don't feel that there is enough time to discuss,' said one juror in the evaluation form after the first day of deliberation. 'I fear this removes some valuable insightful conversation.' 'I thought the

<sup>5</sup> This speaker was a last-minute replacement after the planned speaker was ill.

<sup>6</sup> Kyle Redman and Lyn Carson (2020). *How much time do people need for public deliberation?* newDemocracy Research and Development Note. Available at: <https://www.newdemocracy.com.au/wp-content/uploads/2020/04/RD-Note-Time.pdf>

<sup>7</sup> CFE Research (2020). *The role of lived experience in creating systems change*. Available at: <https://www.bht.org.uk/wp-content/uploads/2021/03/The-role-of-lived-experience-in-creating-systems-change-2020-1.pdf>

whole week was very well put together,’ said another juror on the final day. However, they also found it ‘difficult when the lead facilitators would stop us or rush us... especially when dealing with difficult topics’.

The organisers were conscious of the physical and emotional toll the process took on the jurors. In debriefing sessions, some facilitators raised the possible harm caused by the replication of structural inequalities that exist in society because the design and pace of the process were not specifically adjusted to cater to people dealing with genetic conditions and the physical and emotional toll discussing these topics in depth takes. Some facilitators requested to alter the design of the jury on the final day and give jurors the time to decompress, walk around the campus, and reflect on the process, instead of diving back into crafting recommendations. In the end and after consideration by organisers, this was not implemented. Organisers felt that they had a duty to ensure that the jury could complete their recommendations as promised, and there simply was not sufficient time to do this well as the additional suggested session. The organisers were also aware that there were several jurors who were process-driven and assumed that if the jury finished with no agreed process, this in and of itself would be emotionally draining.

Despite the tight schedule, the organisers insisted upon four fifteen-minute breaks throughout the day and an hour-long lunch as non-negotiable parts of the programme. Jurors were assured that they could take a break whenever needed and genetic counsellors were available on standby throughout the day and evening to offer support and counselling if it was required.

## Debriefing sessions were an open space for reflexive practice.

At the end of each day, facilitators were asked to discuss what they felt went right and did not go quite right in their group deliberations, and what design adjustments can be made to address their concerns. One topic of deliberation, for example, was the seeming disconnect the jurors had with ‘the map’ – a wall of sticky notes that thematizes what excites and worries jurors about genome editing. The lead facilitators used the map as the main reference point in deliberations, asking tables to add themes they felt were not represented on the map, or what topics should be added in the map. Some felt that ‘the map’ did not quite connect with the jurors’ thought processes, while others were concerned that the themes in the map did not directly connect with the remit. The following day, lead facilitators reframed the issues on the map which helped clarify its role to jurors.

Beyond individual issues, a bigger debate took place among the organisers (including the project leader, expert lead, and facilitators) – whether a citizens’ jury was the most appropriate approach for engaging people with lived experience of genetic conditions. One of the main appeals of holding a citizens’ jury is that the randomly selected group of jurors are unlikely to have personal stakes in the issue under discussion – meaning they are also less likely to have fixed, strong views on it, and more likely to be open to deliberation. This process was the opposite – the jurors all had very personal stakes in the topic and the outcomes of the jury. Thus, whilst all citizens’ juries typically find time to be a major pressure point, in this jury time pressure meant moving jurors along through particularly intense and emotionally charged discussions.

This disagreement became clearer in the post-event evaluation among organisers. Some members of the organising team felt that the citizens’ jury ‘was a better format than methods focused on more passive consultation such as surveys, interviews, or focus groups’ and that it was ‘one of the best starting point[s],

but it mustn't be the end point'. Other organisers, meanwhile, recognised the value of a deliberative process on such issues, but the emotive and complex nature of the topic 'may well be beyond the capacity of a CJ to capture'. Another expressed concern about the perceived lack of 'legislative commitment from the government to uphold their recommendations.' At the same time however, the lack of commitment may have been for the best as 'the process did not equally represent a diverse enough sector of society as a whole, or a specific affected group'. These internal discussions demonstrate the reflexivity of organisers in scrutinising their own contribution to supporting the jury process.

Aside from questions about the diversity of the jury, organisers reflected on the appropriateness of the core design features of the jury. One organiser queried the 'majority wins' logic behind the voting process. Even though jurors were reminded that consensus was not the goal of the jury, for one organiser, the fact that the decision-making process required a final vote suggest that 'the majority wins.' Another organiser affirmed this observation – that the process of the jury's decision-making made choices look like a binary process, even though a 0-10 scale was used to map the jurors' final views rather than the originally planned yes/no vote on the question. 'A different method of participatory dialogue should have been pursued,' another organiser added. Meanwhile, another organiser felt that the citizens' jury was a better format than surveys, interviews or focus groups in formulating policy recommendations.

### *Points for Reflection*

- How can a citizens' jury be designed from the perspective of jurors with lived experience of a genetic condition?
- How much control should jurors have in redesigning the process?
- Is a citizens' jury an appropriate approach to citizen engagement given the highly emotive and complex character of the topic?

# CONSIDERATIONS FOR FUTURE CITIZENS' JURIES

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The UK citizens' jury is a part of a wider initiative of implementing similar processes around the world, leading up to a potential global citizens' assembly on genome editing. Here are some considerations for the design and implementation of future citizens' juries.

## Customising the design for patient communities

A citizens' jury composed of members from patient communities with physical disabilities, may need to reconsider some of the core design features of a citizens' jury. For example, a citizens' jury typically requires jurors to sit and deliberate around the table for lengthy periods of time. Jurors are also expected to keep up to a certain schedule to generate recommendations after a certain number of days.

These design features may work for many juries, but a jury composed of members of patient communities may need adjustments. Jurors demonstrated commitment by completing all four days of deliberations despite some jurors' low energy levels and emotional fatigue. Many of them were motivated to continue because they felt the need to get their voices heard as the stakes were high for them. Sitting out some sessions means losing the opportunity to convey their thoughts.

One path forward is to potentially co-design the citizens' jury with members of patient communities, especially those with experience taking part in demanding forms of citizen engagement. It is also possible to give more leverage for the jurors to revisit the terms of the jury as days go by, to check in whether the process is still attuned to their needs and expectations.

## Breaks and 'buffer time' are central to process design

Deliberation is often considered a form of 'slow thinking' but in reality, citizens' juries operate in compressed schedules that demand jurors to absorb information and react to range of perspectives in a short span of time.

One lesson from the UK jury is to consider breaks not just as an auxiliary component of the design but as a central part of the process plan for jurors to recover from cognitively and emotionally taxing work.

Future juries may also build in 'buffer time' or moments when jurors can engage in unstructured activities to prompt reflection, like walking around the venue or doing creative projects to express their emotions. In the UK jury, this option was offered to all participants, although facilitators in one debriefing session advocated for more of such buffer time, especially in later stages of the jury.

## Foregrounding health inequities as a core issue

Diversity, equity, and inclusion have become buzzwords in various policy debates, but for these buzzwords to have meaning in a citizens' jury, they need to be foregrounded as a core issue. This means inviting expert speakers who can help participants develop a vocabulary on health inequities that empower them think through themes from this perspective. Other expert speakers may also be asked to contextualise their testimonies in a highly unequal society. These interventions 'mainstream' equity issues in deliberations as part of the fundamental context, instead of relegating inequities as one of many topics under discussion. It also helps to ensure that the burden of explaining these issues does not fall to jurors with lived experience of health inequities.