

Participant Information Sheet for Jurors



Title of Public Engagement Project: Citizens Jury on Genome Editing of Embryos: Formulating a UK Community Response

Section: Taking Part

This information aims to explain more about a project that you can choose to take part in if you want to. Before you decide, please read this information sheet carefully. Please discuss the study with others if you wish. If you have any questions you can contact us using the details at the end.

We realise the information we are providing is quite detailed so we would like to invite you to take part in a Zoom session to talk all of this through with you and other potential Jurors. Details about joining the project will be provided by Genetic Alliance UK.

Invitation

We are inviting you to be one of the jurors in the British Citizens' Jury on the genome editing of human embryos, which will be held **Tuesday 13th - Friday 16th September, 2022** at the [Wellcome Connecting Science Conference Centre, Hinxton, Cambridge](#).

What is a citizens jury?

This is the name given to an in depth series of workshops where members of the public hear from experts (a bit like hearing from a witness in a court case) and they debate and discuss these (similar to what a jury would do in a court) and then the jury comes to a decision about a policy question. In our case the question being debated is: Are there any circumstances under which the UK Government should consider changing the law to allow genome editing of human embryos?

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As a juror, you will be expected to:

- Travel to [Wellcome Connecting Science Conference Centre, Hinxton, Cambridge](#) and stay over between **Tuesday 13th - Friday 16th September, 2022**.
- Take part in conversations sharing your views. You do not need to have any prior knowledge about genome editing to participate. As a juror, you will have access to further information and expert testimonies during the event itself.
- Participate in filming of the project, including interviews prior, during and after the citizens' jury.
- Agree for your visual image, as captured in the film, to be part of a documentary about the project, which means that this will be publicly available for anyone around the world to see.

You will be paid £800 as an honorarium into your bank account or as vouchers, plus we will pay for your transportation, accommodation, food and childcare costs.

What is the purpose of the project?

Genome editing is the name given to several different technologies that make it possible to alter parts of a person's DNA. DNA is inherited from our parents and contains the instruction that gives us particular characteristics, like our eye colour or height. Altering parts of a person's DNA might help contribute to treating particular genetic conditions. However, it also raises ethical, legal and social implications, particularly when thinking about applying the technology to human embryos.

The main purpose of the Citizens' Jury is to talk to members of the public to understand community preferences and develop recommendations for the use of genome editing in embryos, in the UK. The secondary purposes are to capture the debates in a documentary film to widen the public impact of the process. This is a public engagement project that will lead to the creation of policy recommendations.

What does the project involve?

The project will involve establishing a citizens' jury composed of 25 individuals who are recruited through Genetic Alliance UK - such people may be patients, carers or relatives of

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people with a genetic condition. As a juror, you will have access to the best available information, hear from world leading experts on genome editing and related fields, and deliberate with other jurors on the basic principles that should underpin the regulation of genome editing of embryos in the UK.

On the final day, the jurors will develop a set of concluding statements and recommendations. The team from Wellcome Connecting Science and Involve will use these recommendations to create a final report that will be sent to the Department of Health and Social Care in the UK.

The citizens' jury deliberations will be filmed to make a short documentary about the process. Photographs will also be taken to document the event. The filmed footage and still pictures which will identify your visual image and voice and will be used to promote the outcomes of the jury. A small part of the footage may be used by the Australian production company [GenePool](#) for a Netflix documentary series on Genome Editing.

Who is responsible for this project?

This project is the responsibility of Prof. Anna Middleton and her team of engagement, dialogue and ethics experts at [Wellcome Connecting Science](#), including:

Lauren Robarts
Dr Richard Milne
Damian Hebron
Dr Alessia Costa
Dr Christine Patch
Dr Jonathan Roberts

The study will be run in collaboration with Dr Simon Burall and his team of community engagement experts at [INVOLVE](#). Dr Burall has extensive experience in running similar events and will chair the Citizens Jury together with his colleague Kaelar Scott.

The British Citizens Jury is an engagement and policy project which is part of a larger project, the [Global Citizens Assembly \(GCA\)](#), led by a team of researchers and filmmakers based in Australia. They will not be present during the British Citizens' Jury, but have been involved in setting up the study and have also sought out ethical approval for this project

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from the University of Tasmania, they will contribute to the evaluation of the whole project. They include:

Prof Dianne Nicol (University of Tasmania)
Prof John Dryzek (University of Canberra)
Prof Simon Niemeyer (University of Canberra)
Dr Nicole Curato (University of Canberra)

The GCA will be the main theme of the Netflix documentary series on Genome Editing, which might include footage from the British Citizens' Jury. This part of the project is led by:

Ms Sonya Pemberton (Genepool Productions)
Mr Tony Wright (December Media)

What will happen if I decide to take part?

If you decide to take part, you will be asked to sign a consent form to confirm your agreement to participate. You will be asked to take part in the following activities.

- ***Citizens' Jury***

The citizens' jury deliberations will consist of a mix of large group and small group discussions, as well as presentations from and discussions with experts. The whole event will be facilitated by Dr Simon Burall and Kaelar Scott from [INVOLVE](#). Small group discussions will be facilitated by staff from [Wellcome Connecting Science](#) and supported by Prof Anna Middleton.

The small group and large group discussions will be filmed. Facilitators for each group discussion will take notes. These data will help the jury to shape a series of recommendations about genome editing.

Before, during and after the Jury we will ask you to take part in short, filmed interviews to assess your views and expectations throughout the process. Finally, at the end of the citizens' jury, we will ask you to complete an anonymous evaluation survey to provide feedback on the event. This will help us understand participants' experience and improve the process for future events.

- ***Filming***

A member of our team (Lauren Roberts) will film the entire event, including, but not limited to, the jurors' arrival, experts' presentations, and large and small group deliberations. With

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your consent, you will also have the option to be filmed one-to-one to give your feedback throughout the jury process. Photographs will be taken to record the event.

With your consent, pictures and footage from the event, including your image and/or voice, will be:

1. Used to make a short documentary about the British Citizens' Jury, which will help us to raise awareness on public views on genome editing;
2. Distributed on our website, on social media and for press releases to disseminate findings from the project and widen its impact;
3. Used to aid the creation of a final report summarising the jury, and made available online for anyone to access around the world;
4. In addition, the footage or any parts thereof, might be shared with Ms Sonya Pemberton and her team from the Australian production company GenePool production to be included in the Netflix documentary series on genome editing.

Due to the nature of the Citizens' Jury, participation in the event is conditional upon agreeing to be filmed. This means that it is not possible to take part in the jury without taking part in filming. However, jurors will be able to request not to be filmed at particular times and quiet rooms will be provided for temporary 'time outs' from the main event.

During the introductory Zoom call, you will have the opportunity to see the documentary made by the Australian citizens jury team and meet the filmmaker and hear more about the process. You will be able to ask any questions you may have before deciding if you want to take part.

Privacy and Confidentiality

If you decide to take part, your identity will be known to the project team and to other jurors. The use of your image and/or voice in the film and other study outputs may also make you identifiable to people unrelated to the project.

To protect your privacy, you will be given the opportunity to select by which name you would like to be identified. You can choose your first name or another name of your choice. During the event and in all the study outputs, including the final report and film, you will be identified solely by this name. Please note that by agreeing to be filmed, your visual image will be available freely and so this on its own means your participation is not 'confidential' or 'anonymous'.

Your information may be subject to review for monitoring and audit purposes, by individuals from the Institution and/or regulators who will treat your name/email data in confidence (although after the jury has been delivered, records of your name and email address will be destroyed). Confidentiality of your name and email will be maintained unless there is a

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legally mandated reason for disclosure. However, your visual image is different, in the final finished documentary and in clips from the film, the presence of your visual image will mean your participation is not confidential or anonymous.

What will happen to my data if I decide to take part?

The filmed data will contain your image and/or voice and the name you choose to be identified by. The raw film footage will be securely stored in password protected computers/servers at the Wellcome Genome Campus, Hinxton, where Wellcome Connecting Science is based. It will also be uploaded into film editing software to make the documentary. The data will be securely shared between the film makers, team at Wellcome Connecting Science and with our collaborators at INVOLVE, who will prepare the final report from the study.

Your contact details (e.g. email address) will only be accessible to the Wellcome Connecting Science team. Your email address will be stored for as long as it is necessary to deliver the Citizens Jury and will be deleted afterwards. The raw footage from the filming will be stored for as long as is needed to make the documentary films and prepare the material needed for dissemination of the project.

Other uses of the data

- ***Future analysis***

With your permission, we would like to share the video data, including footage from the event, on the project website for ten years. This will be made accessible to the wider public engagement community and as it will sit on the website it can be accessed, viewed and analysed by anyone around the world.

- ***Global Citizens' Assembly and documentary series***

As mentioned, the British Citizens' Jury is part of a larger project, the Global Citizens' Assembly (GCA), led by a team of researchers and filmmakers based in Australia. It is anticipated that data from the British Citizens' Jury might be analysed as part of pulling together findings for the GCA. Subject to funding, the GCA will take place in 2023, with Jurors from different countries around the world. It is anticipated that the event will be the main theme of the Netflix documentary series being produced by GenePool Production.

To contribute to these aims, we would like your permission to:

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- Share filmed data from the British Citizen Jury with the Australian Research team to conduct their own analysis;
- Share footage from the British Citizen Jury, including your image and/or voice, with Ms Sonya Pemberton to possibly be included in the documentary series on the GCA.
- Share footage from the British Citizens Jury on the project website, in academic presentations of the project and make it freely available to any global audience to access - once it has been shared publicly it will not be possible to withdraw it and we have to expect that it could remain online for many years, even after it has been withdrawn from the project website.

What will happen to the outcomes from the citizens jury?

Your attitudes, values and opinions will form part of a series of recommendations in a final report. This will be distributed widely and will be sent to the Department of Health and Social Care which makes policy for the British government in this area. The policy recommendations may be published in academic journals (e.g. on policy or science communication) or presented at academic conferences. The documentary film may be presented at national and international film festivals and will sit on the project website, it will also be distributed widely around the world and will be freely available for access by anyone. Social media coverage and press releases will be organised to disseminate the findings - these will also include filmed footage from the jury as well as still images from the jury.

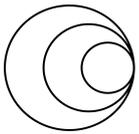
All outputs from the study will be free to access for anyone. They may include direct quotes from your interviews and/or sections of film that includes your visual image and voice. Your image and/or voice may appear in photographs taken at the event and in the documentary film. The data will be attributed to you using only your preferred name of choice; no other identifying details will be included.

All study outputs will be regularly made available on the [project website](#). Please do check the website or contact the research team to find out the results of the study.

What happens if I do not want to take part or if I change my mind?

You can withdraw from the Citizens' Jury at any point without giving reason. If you are unsure about continuing, you can discuss your concerns with the project team or simply inform them of your decision to leave.

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Due to the deliberative nature of the Citizens' Jury, it might not be possible to remove your 'voice' from the recommendations (but we will be able to remove your name, if you had chosen to give it). For example, it will not be possible to change the outcome of a discussion you have participated in. For this reason, we will ask your permission to use any data that has been collected up to the point of your departure, which may include direct quotes as well as your image and/or voice. If you have strong feelings about your data not being used, please do inform the Wellcome Connecting Science team. We will do our best to find a solution that feels comfortable for you. If you choose to withdraw from the jury, part way through, where it is possible we will remove you from any filmed material that has already been gathered. We will also blur your image and disguise your voice if we are unable to fully delete your participation in the film. If you change your mind about being filmed or giving us access to the visual image of you in the film, we will do our best to remove it from the documentary about the project. If you change your mind many months after the documentary has been distributed, it will not be possible to fully withdraw your visual image from the internet.

What are the possible benefits in taking part?

The results of the study will provide valuable insights into the views and values of members of the public about genome editing of human embryos, which can help in the development of the technology and its regulation.

From our conversations with participants in past events similar to this, we expect that you may find the experience personally rewarding.

Will I be reimbursed for my time?

Yes, you will be reimbursed £800 for 4 days of your time. Travel, accommodation, food and childcare costs will be fully covered by the organisers.

Are there any potential risks involved?

A possible disadvantage to taking part in the study is that it may raise sensitive issues, for example regarding the use of human embryos. If you feel uncomfortable, you can decide to pause or withdraw from the study at any point. We will also have trained genetic counsellors present for the jury who can offer genetic counselling support if you feel upset by any of the issues raised. As mentioned, if you decide to withdraw it might not be possible to remove data that has already been collected.

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In order to reduce any potential distress, designated support will be available for participants who might no longer feel to take part, either for short term 'time outs' or to help facilitate their departure. This support is a precaution only, and rarely needs to be called upon in our experience.

In the unlikely event you need additional assistance, you can find details on how to access external support in the section 'Further Information' at the bottom of this document.

The biggest 'risk' from taking part relates to the filming - whilst you may be enthusiastic to start with, you may find that you say things in the jury that you later regret. Please think carefully about whether you want to take this risk and whether you are OK about being filmed to start with. The documentary film will be made with the upmost respect and aims to show the process of discussion around interesting topics. It does not aim to be gratuitous or to present anyone in a bad light. However, you must be aware that if you choose to participate, you may say things in the jury that you later regret and may prefer that this isn't included in the final film. If you feel there is a strong risk of this, or if you have any doubts about being filmed, this isn't the project for you. If you inadvertently say anything that you later regret, where it is possible, we will do our best to locate it in the filmed footage, and not use it in the documentary, but we cannot guarantee this.

How is the project being funded?

This project is being funded by the Wellcome Trust through their grant to Wellcome Connecting Science.

Who has reviewed this project?

The Global Citizens Assembly Project has been approved by the Tasmania Social Sciences Human Research Ethics Committee.

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Section: Your personal data

What is personal data?

‘Personal Data’ means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to the study and this section gives information on that. Personal data collected will include your name and email address, which will be used to communicate with you about the project.

Another category of personal data, called ‘special category personal data’, includes sensitive information about you. This might include information about your ethnic background, religious beliefs, political views, physical or mental health, sexual orientation. We do not need to collect and store any of this data for this project, directly connected to your name, however, you may decide to share some of this information during the deliberations if you feel it is relevant to your opinion on genome editing. If you do choose to share this information it may be picked up in the filming and it may also form part of the discussions.

We are also collecting, storing and distributing your visual image, together with your opinions as part of the filmed documentary. The filmed data will be freely and publicly available to others and so you will be identifiable in this.

Who is handling my personal data?

Genome Research Limited (of which Wellcome Connecting Science is part) has the legal responsibility for the project and will act as the ‘Data Controller’ for the data used in arranging and filming the jury. Genetic Alliance UK will advertise the project for recruitment and will act as ‘Data Controller’ before potential juror’s contact details are handed over to the Wellcome Connecting Science team. Once Genetic Alliance UK has handed over data controllership, GRL will process your personal data on behalf of the controller and are responsible for looking after your information and using it properly. We will use this information as explained in this document.

What will happen to my personal data?

We have to ensure that when we use **identifiable personal** information from people who have agreed to take part in public engagement activities, this data is processed fairly and lawfully. The Institution processes personal data for the purposes of carrying out research

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in the **public interest** and **special category data** is processed on an additional condition necessary for **research purposes**. This means that when you agree to take part in this project, we will use and look after your data in the ways needed to achieve the outcomes of the project.

Your personal data will be processed in accordance with current data protection regulations.

How will we use information about you?

We will need to use information from you for this project.

This information will include your:

- Initials
- Full name
- Preferred name, as of your choice (pseudonyms will not count as personal data)
- Contact details, including email address
- Your filmed image and/or voice

We will use this information to run the citizens jury or to communicate with you. People who do not need to know who you are will not be able to see your full name or contact details. Once we have finished the project, we will delete all records of your full name and email address.

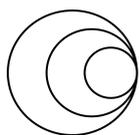
Your image and/or voice will be treated as data that will be included in the study outputs, including the report and documentary film. The data will be shared with our collaborators from INVOLVE and from the Australian Global Citizens Assembly on Genome Editing team, who must follow our rules about keeping your information safe - however, once the filmed material has been shared online, it is not possible for the project team to retain any control over who chooses to look at it. Your full name will not be included in the data and we will only use your preferred name of choice.

As mentioned, we do not need to collect other personal information about you. However, you can decide what information about yourself you may want to share during the Citizens' Jury. Information shared during the Citizens Jury will be treated as public engagement data and will be used as explained above.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

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- in this leaflet
- by asking a member of the project team, either at Wellcome Connecting Science or Genetic Alliance UK as part of the consent process
- by contacting our data protection officer at GRL, please email engage@wellcomeconnectingscience.org and mark the email for the attention of the data protection officer for the citizens jury project

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO) (<https://ico.org.uk/>).

Section: Further information

What if you need support?

As mentioned, dedicated support will be available during the Citizens' Jury. In the unlikely event you need to access external support, you can:

- contact the Samaritans on 116 123 (free from any phone; 24 hours a day, 365 days a year); or email jo@samaritans.org
- Text "SHOUT" to 85258 to contact the **Shout Crisis Text Line**
- consult the NHS urgent mental health helpline (for England only) at: <https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline>

What if you have a query or something goes wrong?

If you are unsure about something you can contact the Wellcome Connecting Science team at any point using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent, then please contact Head of Legals: Jeff Ryen jr34@sanger.ac.uk

If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this project then you should follow the instructions given above.

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Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Chief Investigator: Professor Anna Middleton,
anna.middleton@wellcomeconnectingscience.org
+44 (0)1223 492391

Project manager: Lauren Robarts
lauren.robarts@wellcomeconnectingscience.org
+44 (0)1223 495332

Thank you for reading this information sheet and for considering taking part in this public engagement project.