

Participant information sheet

Project Title: The perceptions and hopes of individuals affected by genetic conditions for gene-editing technology

Invitation

You are invited to take part in a research study which will aim to improve our understanding of what people with a genetic condition think and feel about gene-editing technology. It is completely your decision whether to take part. Before you make your decision please take your time in reading the information provided so that you fully understand what the study will involve. Please feel free to discuss this with friends and family. If you have any questions or would like further information, please contact the email address at the bottom of this sheet.

➤ **What is the purpose of the study?**

We want to better understand how people affected by a genetic condition feel about gene-editing, what they know and their thoughts and opinions about it. We also hope to understand what influences people to think and feel a certain way about gene-editing. Up until now there have already been many studies looking into how the general public think and feel about gene-editing, but so far researchers have not yet focused on people who have a genetic condition, who would arguably be the people to benefit the most from gene-editing.

➤ **Why have I been chosen?**

You have been asked to take part because you are affected by a genetic condition or have inherited a high risk for developing certain types of cancer.

➤ **Do I have to take part?**

No. The study is voluntary and the decision whether to take part is up to you. However, you should only take part if you feel physically and mentally well enough. If you decide to take part, you will be asked to sign a consent form stating you agree to take part. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights or care you receive. You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form.

➤ **What will I have to do in the study?**

The study involves an interview where you will be asked to answer some questions and have a relaxed conversation around them. You are encouraged to speak openly and honestly. The interview will last between 30-60 minutes. With your permission the interview will be audio-recorded and then transcribed. We can arrange the interview at a time, date and place of your choice whether that be face to face or by telephone/video call.

➤ **Will I be paid for taking part?**

No. You should understand that any data you give will be as a gift and you will not benefit financially in the future should this research project lead to the development of a new treatment/method/test/assessment.

➤ **What are the possible benefits and risks of taking part?**

There will be no direct benefits to you from taking part, but your contribution will help us understand the knowledge, perceptions, thoughts and feelings people with a genetic condition have about gene-editing. Some of the topics of discussion may cause you to feel upset. You do not have to answer certain questions if you do not want to and we can pause or end the interview whenever you wish without explanation.

➤ **Will my personal information and participation be kept confidential?**

All information collected about you will be kept strictly confidential in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. Confidentiality will only be breached in exceptional circumstances if legally or professionally required. The research team will notify you if breach of confidentiality is required.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and data protection legislation. Further information about Data Protection can be found using the link below:

<https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

Your personal data will be processed within 3 weeks of receiving it. The transcripts of your interview will be anonymised and will be safely stored by Cardiff University along with your consent form. All other data (contact information, participant survey, interview audio recording) will be deleted once it is no longer needed. You will be assigned an unidentifiable ID and any personal information will be anonymised with the exception of your consent form. Your data will only be shared with the project supervisor, no one else. The anonymised transcript and your consent form will be stored by Cardiff university for 5 years after the study is completed.

➤ **What will happen to the results of the study?**

The results of the study will be used to write a report. Your name and personal details will not be used, and you will be referred to using a made up name (pseudonym). The results of the study will be shared with you if you wish via the support group you were recruited from. The report may then be published as a paper in a scientific journal. You can request a summary of the study once it is complete.

➤ **What if there is a problem?**

If you wish to complain or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact the project lead Emma Osborne. If your complaint is not managed to your satisfaction please contact Dr Marion Mcallister (mcallistermf@cardiff.ac.uk), who is the MSc Genetic & Genomic Counselling course director, to escalate your complaint.

➤ **Who is organising and funding the study?**

The study is not funded. The research is being organised by Cardiff university postgraduate student Emma Osborne with the supervision of Dr Gareth Thomas.

➤ **Who has reviewed this research project?**

This research project has been reviewed and given a favourable opinion by the School of Medicine Research Ethics Committee.

➤ **What do I do next?**

If you would like to take part, please contact the project lead using the email address below. Any questions you have can be answered and an interview can be arranged. You will be sent a couple of forms to fill out including a consent form.

You will need to return these forms by email. These forms are required to tell us a bit about you, to make sure you have understood the study and that you have consented to take part. You will need to read the consent form then sign and date it either by hand then scanning it onto your computer, taking a picture of the signed form or by signing it electronically. These forms must be filled out, signed and returned via email before the interview.

Thank you for taking the time to read this information. If you have any questions, require any further information or would like to take part please contact OsborneE2@cardiff.ac.uk