

Participant Information Sheet

Research Project Title:

“We need to talk”: Social and ethical dialogue around genomics and disability

Researcher(s):

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Thank you for your interest in participating in this research project. Please read the following information about the project so that you can decide whether you would like to take part in this research. Please feel free to ask any questions you might have about our involvement in the project.

If you decide to participate in this project, please keep in mind that your participation is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to stop at any time, and you would not need to give any explanation for your decision to stop participating. If you choose to stop participating, your data will not be used in the research.

Your decision whether you take part, or not to take part, or to take part and then withdraw, will not affect your relationship with the University of Queensland.

What is this research project about?

The aim of this project is to gather information from a range of perspectives (people with lived experience of disability, genomics researchers, health professionals and the general community) about the ethical, legal, and social issues of genomics and disability.

You have been invited to participate in this project because you are;

1. A person with disability and/or a family member and/or a carer of a person with disability
2. A health practitioner
3. A genomics researcher
4. A member of the general community

What will I need to do?

If you agree to participate in this project, you will be asked to complete a survey. The survey can be completed **online** (via an online survey), or via a **paper copy** which can be completed and returned to

the project team using a reply-paid envelope that will be supplied to you. The survey will take approximately 20 to 30 minutes to complete.

The survey contains general demographic questions and questions about:

- Whether you have lived experience of disability and if so, the impact of that disability and other factors on day-to-day life
- Your views about the benefits and issues related to prenatal testing for people with disabilities
- Your views of the use of gene therapies to cure disabling conditions
- Your views on the terminations of pregnancies because of pre-natal testing

In most instances, the questions require that you to choose one response. For example, using a scale from 0 (*strongly disagree*) to 4 (*strongly agree*), to rate how much you agree with a statement about genetic testing. In other instances, some questions may ask you to provide a short, written response. You can skip any question you do not feel comfortable answering.

Your participation in this project is anonymous. Return of a completed survey online or via paper copy will constitute your **consent** to participate in this project. Online survey participants will also need to tick a box confirming their anonymous consent to participate.

What are the possible benefits of taking part?

Participants who complete the survey in full can **enter a raffle** to win one of five \$100 Coles Myer Gift Cards. In addition, the information you provide will be used to inform genomic policy, research, education and practices in relation to people with disabilities.

What are the possible risks and disadvantages of taking part?

It is anticipated that there are **no risks or disadvantages** associated with your participation in this project. However, from time to time, some people may become uncomfortable, upset, or distressed after completing surveys that ask questions about genetic testing or termination of pregnancy. If you experience any discomfort or distress, please contact either Karen Nankervis (phone: 07 3365 6493, email: k.nankervis@uq.edu.au) or Maria Vassos (phone: 0413 769 142, email: m.vassos@uq.edu.au). They will confidentially talk through your concerns and suggest appropriate follow up if required.

If you would like to speak to someone independent of the project, please contact Lifeline (phone: 13 11 14) or Beyond Blue (phone: 1800 224 636).

What will happen to the information about me?

All information provided by you will be kept private and confidential. Paper data will be stored in a locked cabinet in the office of Professor Karen Nankervis within of the School of Education at the University of Queensland and will be destroyed after five years. Electronic data will be stored on the University of Queensland's password protected Research Data Manager for a period of five years and will be securely deleted after this time.

It is anticipated that the results of this project will be published and/or presented in a variety of forms. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

What will happen if I decide to withdraw?

Your participation in this project is voluntary and you are free to withdraw from the project anytime without needing to provide any explanation, and you will not receive any penalty or bias as a result of your withdrawal. If you would like to withdraw from this project, please contact Maria Vassos via phone (0413 769 142) or email (m.vassos@uq.edu.au).

Should you decide to withdraw, all the information collected from/about you will be destroyed and will not be used in the project as long as it can be reliably identified in the anonymous dataset using your reported demographic information.

Can I hear about the results of this research project?

If you would like to receive a plain language summary of project findings at the completion of the project, please register your interest by contacting Maria Vassos via phone (0413 769 142) or email (m.vassos@uq.edu.au).

Project findings will be written into several research articles to be submitted for publication in peer-reviewed scientific journals. The research findings will also be presented at research conferences in Australia and internationally. The results of this project will also be published on 'We Need to Talk' project website: <https://hass.uq.edu.au/research/we-need-to-talk>

Who can I contact if I have any concerns about the project?

This study adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. The Ethics ID number for this project is: 2021/HE001821

Whilst you are free to discuss your participation in this study with the lead researchers (email: weneedtotalk@uq.edu.au), if you would like to speak to an officer of the University of Queensland not involved in the study, you can contact the Ethics Coordinator via phone on 07 3365 3924 or 07 3443 1656, or via email (humanethics@research.uq.edu.au).