**Participant Information Sheet**

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|  | We are looking for people to take part in the **‘We Need to Talk’** project. |
| Icon  Description automatically generated with medium confidence | This document will tell you about the project.  It will also tell you how you can take part in the project. |
|  | Researchers from the University of Queensland are doing this project. |
| A person wearing glasses  Description automatically generated with medium confidence | The researchers are:   * Karen Nankervis |
| Associate Professor Rhonda Faragher - School of Education - University of  Queensland | * Rhonda Faragher |
| **A person wearing glasses  Description automatically generated with medium confidence** | * Maria Vassos |

## About the “We Need to Talk” project

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| A person holding a sign  Description automatically generated | This project is about **genetics** and **people with disability**. |
| A picture containing person  Description automatically generated | **Genetics** is about how **genes** are passed from parents to children. |
| A picture containing person, striped, dark  Description automatically generated | Genes have information that decide:   * What our bodies may look like. * If we might have health problems. * If we might have a disability. |
|  | A person’s body is made of lots of cells. |
| Logo, company name, arrow  Description automatically generated | Genes are found in the cells that make up a person’s body. |
|  | There are tests that help us to understand a person’s genes.  These tests are called **genetic tests**. |
| A picture containing text, indoor, close  Description automatically generated | A person’s blood or saliva is tested. |
|  | Some genes can cause a person to have a disability. |
|  | Genetic tests can tell us if a person has genes that cause disability. |
|  | People of **any age** can have a genetic test, even unborn babies. |

## What are we going to do?

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| A picture containing text, person, person  Description automatically generated | We want to know what people with disabilities think about genetic tests. |
|  | We will ask **people with disability** what they think. |

## I want to participate. What do I need to do?

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| A person holding her hand up  Description automatically generated with low confidence | People can choose **how** they want to tell us about their ideas. |
| A picture containing text, electronics, computer  Description automatically generated | People can fill out an **online survey.** |
| Two people sitting at a table with a computer  Description automatically generated with medium confidence | People can come to an **interview** to speak about their ideas. |
| A close-up of a stopwatch  Description automatically generated with low confidence  A black and red alarm clock  Description automatically generated with low confidence | The online survey takes between 20 and 30 minutes to complete. |
|  | If you need help with the online survey, please ask one of your support people to help you. |
| A person wearing glasses  Description automatically generated with medium confidence | If you want to participate in an interview, please contact Karen. |
| A person talking on a cell phone  Description automatically generated | You can call Karen on (07) 3365 6439. |
|  | You can email Karen: [k.nankervis@uq.edu.au](mailto:k.nankervis@uq.edu.au) |

## About the Interview

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|  | Interviews will last around 60 minutes. |
|  | If you want, you can bring a support person to the interview. |
| Associate Professor Rhonda Faragher - School of Education - University of  QueenslandA person wearing glasses  Description automatically generated with medium confidence  **A person wearing glasses  Description automatically generated with medium confidence** | We can also **help** you if you need help to talk to us. |
|  | We can do the interview at a place that you know and feel comfortable in. |
|  | We can also do the interview online via Zoom. |
|  | It is OK to say that you do not want to answer a question we ask you. |
|  | If you feel upset during the interview, please tell us so we can stop the interview. |
|  | We will audio record your interview. |
|  | We will listen to the recording of the interview and take notes. |
|  | We will delete the audio recording after we have taken notes. |
|  | Any information we collect from you will be kept private. |
|  | Information that we write down will be locked in a cabinet that only we can access. |
|  | If we put any information into a computer, only we can access that computer. |
|  | All the information we collect will be put together in a report. |
| A person holding a drawing  Description automatically generated with medium confidence | We will not mention your name in the report. |
|  | As a thank you, you can enter a raffle to win a $100 Coles Myer gift card. |
| Graphical user interface  Description automatically generated with medium confidence | We will put together a summary of findings from the project. |
|  | If you would like to receive a copy of the summary, you can tell us at the end of your interview. |

## Do I have to agree to take part?

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|  | **No,** and no one will think badly of you if you do not want to be involved. |

## IF you say ‘YES’ to being involved:

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|  | You can stop being a part of the project at any time. |
| Chart  Description automatically generated | If you decide to stop, we will not use your information in the project. |
|  | You can talk to anyone you want about your interview. |

## How will this project help people with a disability?

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| A person holding a computer  Description automatically generated with medium confidence | With the help of people with disability, we want to: |
| A computer and a tablet  Description automatically generated with low confidence | Make **information sheets** about genetic tests.  A fact sheet gives people key information about a topic. |

## I have questions. Who can I contact?

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| A person wearing glasses  Description automatically generated with medium confidence | Karen can answer any questions you have about the project. |
| A person talking on a cell phone  Description automatically generated | You can call Karen on (07) 3365 6439. |
| Graphical user interface, application, Teams  Description automatically generated | You can email Karen: [k.nankervis@uq.edu.au](mailto:k.nankervis@uq.edu.au) |
|  | The University of Queensland has said it is OK for us to do this study.  You can also talk to a person from the University of Queensland about this study. |
| A person talking on a cell phone  Description automatically generated | You can ring the Ethics Coordinator on  (07) 3365 3924 or (07) 3443 1656 |
| Graphical user interface, application, Teams  Description automatically generated | You can email the Ethics Coordinator:  [humanethics@research.uq.edu.au](mailto:humanethics@research.uq.edu.au) |