

## Participant Information Form



### ***Researchers involved in the project:***

Dr Kiah Evans (Program Manager Autism Research Team)  
Dr Amy Finlay-Jones  
Narelle Mullan (Program Manager FASD Research CRE)  
Professor Carol Bower (Epidemiologist)  
Professor Andrew Whitehouse  
Clinical Associate John Wray (Developmental Paediatrician)  
Jacinta Freeman (Research Assistant)

### ***Project Title:***

Working Towards a Shared Framework in the Diagnosis of Neurodevelopmental Conditions in Australia: A Gap Analysis

### ***Invitation:***

You are invited to participate in a gap analysis project in relation to the screening, assessment, diagnosis and referral processes for neurodevelopmental conditions in Australia. You are asked to take part in this project because you are either an adult with a neurodevelopmental condition or you care for individual(s) with a diagnosed neurodevelopmental condition or you have experience as a professional working with individuals with a diagnosed neurodevelopmental condition

### ***What is this project about?***

The aim of this project is to understand what is needed to create an integrated framework to guide screening, assessment, diagnosis and referral for neurodevelopmental conditions. Individuals with a neurodevelopmental conditions, caregivers of individuals with a neurodevelopmental condition and professionals with experience with neurodevelopmental conditions, will be consulted in order to understand the benefits, challenges and needs related to developing a shared framework in this field.

### ***What does participation involve?***

Participation in the research involves completing a brief survey and/or attending a workshop (either or both option can be selected).

Participation through completing a brief survey involves answering the following question through the research project webpage, *"How can the processes of assessing and diagnosing neurodevelopmental conditions in be improved?"* You will also be asked to answer several brief survey questions describing your characteristics, such as experience with neurodevelopmental conditions and broad location. You will be invited to provide an email address so that we can clarify aspects of your response if required and share the research findings.

Participation through attending a workshop includes attendance at either a Community Conversations workshop (if you have lived experience of neurodevelopmental conditions) or a Consultative Workshop (if you have professional experience working with individuals with a diagnosed neurodevelopmental conditions). The workshops will take 3 hours and will explore and seek to better understand the experiences of screening, assessment, diagnosis and management processes of neurodevelopmental conditions. These workshops will be audio-recorded to assist with transcribing findings and outcomes. Please advise the facilitator if you do not want your voice to be recorded. Please advise the facilitator if you do not want your voice to be recorded. You will need to provide your first name and email address when registering for the workshop, so that we can remind you of the workshop details and share the research findings.

### ***Voluntary Participation and Withdrawal from the Study***

Participation in this research is voluntary and completing the survey or responding that you will attend a workshop is considered evidence of consent to participate in the study. You can withdraw from the study at any time, without giving an explanation and without having any consequence on any service or affiliation. If you have not provided your name or email address, it will not be possible to withdraw from the study once you complete the survey. If you withdraw from the research, any data that is identified as being provided by you will be destroyed unless otherwise agreed.

### ***Your privacy***

Your participation in this study and any information you provide will be treated in a confidential manner. Information from this project may be published in summary reports, conference presentations, media and academic publications. The data will be kept in a de-identified format, in a password protected computer or a secure server for minimum seven years.

### ***Possible Benefits***

Participating in this project will give researchers a better understanding of the benefits and challenges of developing a shared framework for the processes of screening, assessing, diagnosing and referring neurodevelopmental conditions. This may benefit consumers and clinicians as the understanding will better inform as shared framework.

### ***Reimbursement***

Participants who have lived experience of a neurodevelopmental condition will be offered a \$50.00 gift voucher for participating in the Community Conversation workshop.

### ***Possible Risks and Risk Management Plan***

There are minimal foreseeable risks associated with this research. It is possible that participants may experience inconvenience due to time spent on the project. Participants may also feel distressed upon recalling or discussing their experiences associated with a neurodevelopmental condition. All workshops will be attended by researchers with allied health or medical backgrounds, and participants will be provided with support and links to relevant professional service if they show signs of distress.

Please be reassured that participating in this project will in no way influence your involvement in other Telethon Kids Institute project.

### ***Approval***

Approval to conduct this research has been provided by the University of Western Australia (RA/4/20/4314), in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time.

In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics Office at the University of Western Australia on (08) 6488 3703 or by emailing to [humanethics@uwa.edu.au](mailto:humanethics@uwa.edu.au)

All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.

### ***Contact***

If you would like to participate or discuss any aspect of the study please feel free to contact Kiah Evans on either 9489 7662 or [kiah.evans@telethonkids.org.au](mailto:kiah.evans@telethonkids.org.au).