

Project title: Developing a National Guideline for Autism Spectrum Disorder Diagnosis in Australia

Name of Researchers:

- Professor Andrew Whitehouse (Speech Pathologist)
- Clinical Associate Professor John Wray (Developmental Paediatrician)
- Professor Margot Prior (Psychologist)
- Professor Valsamma Eapen (Child Psychiatrist)
- Dr Kiah Evans (Occupational Therapist)
- Ms Emily D'Arcy (Occupational Therapy Honours Student)
- Dr Marita Falkmer (Special Educationalist)
- Professor Torbjorn Falkmer (Occupational Therapist)

Invitation:

You are invited to participate in a project to develop a national guideline for autism spectrum disorder (ASD) diagnosis in Australia. We would like you to be involved, as we would like to hear what you have to say about ASD in your community. This will help us to develop guidelines that will include Aboriginal adults.

Aim of the Study (What is the project about?)

The aim of this research project is to develop a national guideline for ASD diagnosis in Australia. The guideline will be suitable for everyone and it will be available to everyone. It will be launched in September 2017. This research project will involve four research studies that will help us identify the most important things to be included in an ASD diagnostic assessment:

1. Steering Committee – this will include an Aboriginal person
2. Consultation Study – when we will be talking to you
3. **Viewpoint Study – this will include Aboriginal teenagers / adults with autism and their caregivers (this research study)**
4. Delphi Study – this will include Aboriginal service providers

What does participation involve?

Participation in the research involves completing a viewpoint survey, either on a computer or hand written. It is expected this will take about 45 minutes. You will be asked to arrange statements on a grid from least important to most important to include in an ASD diagnostic process. You will also be asked to answer several short survey questions, such as why you are interested in ASD and what state or territory you live in.



Voluntary Participation and Withdrawal from the Study

Participation in this research is voluntary, which means you do not need to complete this survey if you do not want to. Completing the viewpoint survey shows that you agree to participate in the study. Because we do not ask you to provide your name, it is not possible to withdraw from the study once you have submitted your viewpoint survey.

Your privacy

You will not be asked to provide your name or any other details that could be used to identify you, such as your address, place of education or workplace. Your participation in this study and any information you provide will be kept confidential. Information from this study will be included in the final guideline, and may be included in summary reports, conference presentations, media and academic publications. The information collected will be kept in a format without personal details, in a password protected computer for a minimum seven years.

Possible Benefits

The benefit of participation in this research is the opportunity to contribute to the development of Australia's first national guideline for the diagnosis of ASD. It is anticipated this will lead to real benefits for individuals with ASD, their caregivers, service providers and the Australian government.

Possible Risks and Risk Management Plan

There are no foreseeable risks of harm or discomfort associated with the research. However, if you become upset from talking about your experiences of ASD the research team can help by linking you to an appropriate support service. Please contact Kiah Evans (Project Coordinator) on either (08) 9489 7662 or Kiah.Evans@telethonkids.org.au to access support.

Contacts

If you would like to participate or discuss any aspect of this study please feel free to contact Kiah Evans (Project Coordinator) on either (08) 9489 7662 or Kiah.Evans@telethonkids.org.au.



Sincerely,

National Guideline Project Team:

Professor Andrew Whitehouse
Clinical Associate Professor John Wray
Professor Margot Prior
Professor Valsamma Eapen
Dr Kiah Evans

Approval to conduct this research has been provided by the University of Western Australia with reference number RA/4/1/8711, 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 UWA on (08) 6488 4703 or by emailing to 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.

The University of Western Australia
M459 Perth WA 6009 Australia

T +61 8 6488 7887
M +61 000 000 000

E aeo@uwa.edu.au
CRICOS Provider Code 00126G