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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. You are asked to take part in this project because it is important for adolescents on the autism spectrum to have input into this guideline.

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 goal is that this guideline would define a diagnostic process that is rigorous, accessible, client-centred, clinically acceptable, effective, efficient, and equitable for individuals being assessed for ASD. The final guideline will be launched in September 2017. In addition to a reviewing the existing literature and seeking feedback, this research project will involve four research studies to identify the most important things to be included in an ASD diagnostic assessment:

1. Steering Committee
2. Consultation Study
3. **Viewpoint Study (this research study)**
4. Delphi Study

What does participation involve?

Participation in the research involves completing a viewpoint survey, either online or in a Microsoft Word document (handwritten or typed). It is expected this will take approximately 45 minutes. You will be asked to arrange a series of statements on a grid from least important to most important, in response to the prompt “It is important that the autism spectrum disorder diagnostic process includes the following...” You will also be asked to answer several brief survey questions about yourself.

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. As you are under the age of 18 years old, you will need to ask your parent or guardian to provide consent for you to participate in the research study. If you do not have a parent or guardian that you are able to ask to provide consent, you may contact the Project Coordinator (details below) to discuss participating in the research study. Completing the viewpoint survey is considered evidence that you have provided consent to participate in the study. We will not ask you to provide your name, so the information collected will be anonymous. Because of this, 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 or school. Your participation in this study and any information you provide will be treated in a confidential manner. 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 or a secure server for a minimum seven years.

Possible Benefits

The potential benefit of taking part in this research is the chance to play a role in the development of Australia’s first national guideline for the diagnosis of ASD. The guideline that will be developed as a result of this research project will be based on research evidence and asking for input from a wide range of stakeholders, hence will be relevant, fair and of high



quality. It is anticipated this will lead to long lasting benefits for individuals on the autism spectrum, their caregivers, service providers and the Australian government.

Possible Risks and Risk Management Plan

We do not expect that there will be any risks of harm or discomfort by completing this survey, and any risks that we can imagine would be no more than the inconvenience of spending time to take part in the research.

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.

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