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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 deemed essential to draw on the perspectives of caregivers during the research and guideline development processes. Caregivers in this study are defined as people who have been providing some form of unpaid care or assistance to an individual with a diagnosis of ASD under the DSM-5 (or equivalent DSM-IV diagnosis) for at least one hour / week for six months.

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 comprehensive literature review and feedback cycle, this research project will involve four interrelated research studies in order to identify the most important components 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 describing the characteristics of yourself and the individuals with ASD to whom you provide unpaid care or assistance.

Voluntary Participation and Withdrawal from the Study

Participation in this research is voluntary and completing the viewpoint survey is considered evidence of consent to participate in the study. As the information collected will be anonymous, it is not possible to withdraw from the study once you have made your submission.

Your privacy

You will not be asked to provide your name or any other potentially identifying details, and your participation in this study and any information you provide will be treated in a confidential manner. Information from this project will be published in the final guideline, and 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

The potential 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. The guideline that will be developed as a result of this research project will be based on research evidence and extensive stakeholder consultation, hence will be relevant, fair and of high quality. It is anticipated this will lead to durable 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, and any foreseeable risk is 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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