

Participant Information Form

A draft framework for approaches to non-standardised assessment for intellectual disability

Lead Researcher

Name: Dr Karen Oakley, Clinical Neuropsychologist & Senior Lecturer in Educational Psychology

Faculty: Faculty of Education & School of Psychology, Faculty of Health

Email: karen.oakley@canberra.edu.au

Project Aim

The aim of this research is to gather feedback on a draft framework to guide psychologists considering a diagnosis of intellectual disability where intellectual functioning cannot be established through standardised IQ assessments.

General Outline of the Project

The information gathered through this project will be used to refine the draft framework for assessing intellectual functioning when standardised assessments of IQ cannot be used. This may help reduce barriers to diagnosis and therefore increase access to intervention and ultimately improve outcomes for people with intellectual disability.

Funding comes from the University of Canberra ReD IGNITE (Researcher Development: Instilling Growth and Nurturing Innovation through Training and Education) program and consultancy fees paid to the lead researcher.

Participant Involvement

If you agree to participate in the research, you will be asked to give feedback on the draft framework for non-standardised assessment of intellectual functioning for the purpose of intellectual disability assessment.

You can choose how you participate in this study:

1. Complete an online survey.
2. Engage in an interview in person or online with a member of the research team.
3. Engage in a focus group of 2-4 people in person or online facilitated by a member of the research team.

If you select option 2 or 3, you will be asked to complete some general questions about your psychological practice through the survey first.

People who participate in an interview may request a copy of their recorded interview and/or transcript.

Participation in the research is completely voluntary, and participants may, without any penalty, decline to take

part or withdraw at any time without providing an explanation. Participants may also choose to not answer any question.

If you complete an interview or provide contact details within the survey, it may be possible to withdraw your responses prior to the completion of data analysis and distribution of results by contacting the lead researcher, Dr Karen Oakley. Surveys completed anonymously will not be able to be withdrawn once submitted. Focus group participant data will not be able to be withdrawn as the contributions will form part of the whole focus group data.

As a participant, you may request to receive a copy of the study outcomes and/ or be contacted about future stages of the study.

Benefits of Participation

There will be no direct benefit to you from participation in this survey. However, your participation may contribute to furthering the assessment practices of psychologists and through this the experience of people presenting for an assessment of intellectual functioning.

Risks of Participation

We estimate the survey will take up to 30 minutes to complete. We recommend you complete the survey on a PC or laptop or equivalent as it involves written responses.

Should you participate in an interview, this will take approximately 60 minutes. Focus groups will take 60-90 minutes.

In thinking about your experiences, particularly if they have not been positive, you may experience some distress. To assist with this, you can stop participating at any time or choose not to answer particular questions. You can also debrief with the lead investigator, Dr Karen Oakley who is a Clinical Neuropsychologist at any time, or we recommend seeking peer supervision or tapping into your other professional support mechanisms.

As is the obligation of all Registered Psychologists, if unethical clinical practices are disclosed during the study, the research team is required to follow the processes specified by AHPRA.

Confidentiality

Only the researchers will have access to the individual identifiable information provided by participants. Privacy and confidentiality will be assured at all times. The research outcomes may be presented at conferences and written up for publication. However, in all these publications, the privacy and confidentiality of individuals will be protected.

Anonymity

Reports and publications of the research will not contain information that can identify any individual, and all information will be kept in the strictest confidence.

Data Storage

Survey data will initially be collected and stored in the online system, Qualtrics, through a University of Canberra log-in or through Mentimeter. Interviews will be transcribed with the assistance of ethics approved software/applications. All data collected including original interviews, transcripts and the downloaded survey data will be stored securely on the password protected University of Canberra supported OneDrive, accessible only through an organisational login throughout the project and for the required five-year period, after which it will be destroyed according to university protocols.

Future Research

If you agree, the information collected during the conduct of this research may be used in future research projects on related research areas. Any future use of your data will comply with any conditions imposed by the Human Research Ethics Committee of the University of Canberra.

Research Team

Dr Karen Oakley, Faculty of Education & School of Psychology, Faculty of Health, University of Canberra
Anastasia Davy, Research Assistant, School of Psychology, Faculty of Health, University of Canberra

Ethics Committee Clearance

The project has been approved by the Human Research Ethics Committee of the University of Canberra (HREC – 114213).

Queries and Concerns

Queries or concerns regarding the research can be directed to Dr Karen Oakley (karen.oakley@canberra.edu.au).

If you have any complaints or reservations about the ethical conduct of this research, you may contact the University of Canberra's Research Ethics & Integrity Unit team via telephone 02 6206 3916 or email humanethicscommittee@canberra.edu.au or researchethicsandintegrity@canberra.edu.au

Consent Form

A draft framework for approaches to non-standardised assessment for intellectual disability

Consent Statement

I have read and understood the information about the research. I am not aware of any condition that would prevent my participation, and I agree to participate in this project. I have had the opportunity to ask questions about my participation in the research. All the questions I have asked, have been answered to my satisfaction.

Please indicate your agreement to participate in each of the following parts of the research (please indicate which parts you agree to by putting a cross in the relevant box):

- Complete a survey.
- Participate in an interview with the researcher.
- Participate in a focus group.
- Agree to have the interview/focus group recorded.
- Agree to the information being used in future research.

Name.....

Signature.....

Date

A summary of the research outcomes can be forwarded to you when published. If you would like to receive a copy, please include your email address below.

Email