

## PARTICIPANT INFORMATION SHEET

### Evaluation of the Intellectual Disability Mental Health Core Competency Toolkit

#### Invitation

You are invited to participate in a survey evaluating the 'Intellectual Disability Mental Health Core Competency Framework: A Practical Toolkit for Mental Health Professionals', developed by the Department of Developmental Disability Neuropsychiatry, UNSW Sydney, with funding and support from the Mental Health and Drug & Alcohol Office, NSW Ministry of Health. This Toolkit outlines how mental health professionals can develop the core competencies outlined in the Intellectual Disability Mental Health Framework to work effectively with people with an intellectual disability and co-occurring mental ill health. It also provides practical information on resources and assessment tools.

Over 400 000 Australians have an intellectual disability and the majority of these individuals (57%) have a psychiatric disability or mental disorder. However, despite both the frequency and complexity of their mental health care needs, people with an intellectual disability experience significantly lower rates of participation in preventative health initiatives, illness and disease detection, and treatment of mental health problems. One of the significant contributors to this population's inequitable access to mental health care is that the mental health workforce feels ill-equipped to meet their needs.

The study is being conducted by Professor Julian Trollor from the Department of Developmental Disability Neuropsychiatry at UNSW Sydney.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

#### 1. What is the purpose of this study?

The purpose is to collect feedback on the utility of the Toolkit in supporting practice. This will help us to develop similar resources and documents in future.

#### 2. Why have I been invited to participate in this study?

You are eligible to participate in this study because you indicated that you hold a mental health clinical, supervisory, managerial or educator role when you completed the questions to access the Intellectual Disability Mental Health Core Competency Toolkit.

**3. What does participation in this study involve?**

If you agree to participate in this study you will be asked to complete an online survey which will take approximately 5 minutes. Alternatively, we can send a paper-based version for completion if you would prefer. Please contact the Project Officer to request this. The survey will ask how useful you found the Toolkit, whether it was relevant to your work role, and what aspects you found positive, and whether you would suggest any improvements. *Please note you do not need to have worked directly with people with an intellectual disability to participate in this survey.*

In nine months (12 months after you downloaded the Toolkit), we will send you an email asking you to complete a follow-up survey. This will contain similar questions to the first survey.

**4. What if I don't want to take part in this study, or if I want to withdraw later?**

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. It will not affect your relationship with UNSW Sydney or the NSW Ministry of Health. However, it may not be possible to withdraw your data from the study results if these have already had your identifying details removed. You can withdraw from the study by contacting the Project Officer (details below). If, when we contact you about the three and 12 month follow-up surveys, you no longer wish to participate, please contact the Project Officer.

**5. How is this study being paid for?**

The study is being paid for by Mental Health Kids, NSW Ministry of Health.

**6. Are there risks to me in taking part in this study?**

There are negligible risks associated with participating in this study. After completing this survey you may identify that you require additional information and training in the area of intellectual disability mental health. If this occurs, there is a comprehensive list of resources you can access and training opportunities (e.g. books and E-learning) listed in the Intellectual Disability Mental Health Core Competency Framework and Toolkit. It may be inconvenient that we ask you to complete a short follow-up survey nine months after you complete the first survey.

**7. What happens if I suffer injury or complications as a result of the study?**

If you require treatment or suffer loss as a result of the negligence of any of the parties involved in the study you may be entitled to compensation; the cost of your treatment would have to be paid out of such compensation.

**8. Will I benefit from the study?**

This study aims to improve future mental health care for people with an intellectual disability. The findings of this survey may assist the researchers and the NSW Ministry of Health to refine the Toolkit that provides practical information on developing skills and knowledge required to assist people with intellectual disability and mental health issues, and improve strategies to address professional development in this area.

**9. Will taking part in this study cost me anything, and will I be paid?**

Participation in this study will not cost you anything, nor will you be paid.

**10. How will my confidentiality be protected?**

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Your name and email address will be stored separately from your survey responses, linkable only by a participant code. Only the Project officer will access your name/email to send out follow-up surveys. While your name/email address could potentially be linked back to your survey data, when the survey data is being analysed, the researcher will not see your name/email address so will not be able to identify who gave particular responses. Only the researchers will have access to your details and results that will be held securely at UNSW Sydney. This data will be stored in adherence to UNSW Sydney IT Security Standards & Guidelines policy. This will include the storage of any paper-based information in a dedicated, lockable cabinet. Electronic data will be stored on a server which requires authorisation to gain access.

**11. What happens with the results?**

If you give us your permission, we plan to discuss the overall project results with the NSW Ministry of Health and publish the findings at relevant conferences and in peer reviewed journals. At no stage will your individual responses to survey questions be shared with the NSW Ministry of Health. We will also provide you with a written summary of the key survey outcomes if you wish. In any discussion or publication, information will be provided in such a way that you cannot be identified.



**12. What should I do if I want to discuss this study further before I decide?**

When you have read this information, if you would like to know more at any stage, please do not hesitate to contact Claire Eagleson, Project officer at [c.eagleson@unsw.edu.au](mailto:c.eagleson@unsw.edu.au) or (+612) 9931 9160.

**13. Who should I contact if I have concerns about the conduct of this study?**

This study has been approved by the South Eastern Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Research Support Office which is nominated to receive complaints from research participants. You should contact them on 02 9382 3587, or email [RSOseslhd@sesiahs.health.nsw.gov.au](mailto:RSOseslhd@sesiahs.health.nsw.gov.au) and quote HREC ref no: 15/196 (LNR/15POWH/477).

**Thank you for taking the time to consider this study.  
This information sheet is for you to keep.**

## CONSENT QUESTION

### Evaluation of the Intellectual Disability Mental Health Core Competency Toolkit

1. I agree to participate in the study described in the participant information statement set out above
2. I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation.
3. Before starting the survey, I am aware that I can ask questions if I require further information by contacting the Project Officer, Claire Eagleson, on [c.eagleson@unsw.edu.au](mailto:c.eagleson@unsw.edu.au) or telephone (+612) 9931 9160. I am satisfied with the information I have received regarding any possible risks as a result of my participation.
4. I understand that I can withdraw from the study at any time without prejudice to my relationship to UNSW Sydney.
5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.
6. I understand that if I have any questions relating to my participation in this research at any time, I may contact Claire Eagleson, Project Officer on [c.eagleson@unsw.edu.au](mailto:c.eagleson@unsw.edu.au) or telephone (+612) 9931 9160, who will be happy to answer them.
7. I understand I can download a copy of the participant information sheet and consent form from [www.3dn.unsw.edu.au](http://www.3dn.unsw.edu.au).

Complaints may be directed to the Research Support Office, South Eastern Sydney Local Health District, Prince of Wales Hospital, Randwick NSW 2031 Australia (phone 02-9382 3587, fax 02-9382 2813, email [RSOseslhd@sesiahs.health.nsw.gov.au](mailto:RSOseslhd@sesiahs.health.nsw.gov.au)).

### I consent

- Yes
- No [directs to Framework/Toolkit download link]



[The Revocation of consent form will be available at [www.3dn.unsw.edu.au](http://www.3dn.unsw.edu.au).  
Alternatively, the participant can contact the Project Officer directly to revoke their consent.]

## Evaluation of the Intellectual Disability Mental Health Core Competency Toolkit

### REVOCATION OF CONSENT

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with UNSW Sydney or the NSW Ministry of Health.

Signature of participant

Please PRINT name

Date

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

The section for Revocation of Consent should be forwarded to Prof Julian Trollor at 3DN UNSW Sydney, 34 Botany Street, UNSW Sydney, NSW 2052 or [j.trollor@unsw.edu.au](mailto:j.trollor@unsw.edu.au).