

Participant Information Sheet

Title	<i>NDIS and the lived experience of presenting to the emergency department for people with a psychosocial disability: a mixed methods study.</i>
Project Sponsor	MIND Australia
Chief Investigator/Principal Investigator	Heather McIntyre
Supervisors	Professor Nicholas Procter; Dr Mark Loughhead; Dr Laura Hayes;

Introduction – What does my participation involve?

You are invited to participate in a research project exploring experiences in the Emergency Department. This research is being conducted by a team of researchers from the University of South Australia (UniSA), funded by MIND Australia. Participation in this research is voluntary. If you don't wish to take part, you don't have to. This Participant Information Sheet tells you about the research project and explains the processes involved. Knowing what is involved will help you decide if you want to take part in the research.

What is the purpose of this research?

Psychosocial disability has been included in the National Disability Insurance Scheme (NDIS) since its inception, yet many of the fundamental design features of the scheme were developed without reference to the needs of this population. People with a psychosocial disability may at times become unwell and need emergency care. Exploring how this affects their NDIS plan and continuity of care is the aim of this research. People with a psychosocial disability have particular needs within several converging health care systems. Although previous research has looked at the hospital experiences of people with disabilities, to our knowledge no one has yet explored the more specific issue of people with psychosocial disabilities in hospital emergency departments.

Who is being invited to participate?

People with a psychosocial disability and an NDIS plan, and who have presented at a hospital emergency department within the last two years.

What does participation in this research involve?

You will be invited to participate in a national anonymous online survey which will take between 15 – 25 minutes. Before participating in the survey, you will be asked to read this information sheet, contact the research team to clarify any questions you may have and to acknowledge consent at the beginning of the survey. At the end of the survey you will be asked if you would like to enter a draw to win one of five \$50 gift cards.

What are the possible benefits of taking part?

We cannot guarantee that you will receive any benefits from this research; however, this research (your story) will provide hospital policy makers with recommendations concerning best practice and pathways to continuity of care, based on the lived experiences of people requiring care. What are the possible risks and disadvantages of taking part?

The risks are minimal, but nevertheless there is some risk. The research team will not be asking you to necessarily provide specific details of your experiences in the emergency department (as this could be retraumatising) but will ask your opinion on what worked well and what were the challenges you faced. You may have a support person assist you if you choose. The online survey is intended to be anonymous. The researcher will take every care to

keep data confidential. However, confidentiality of anonymous data stored on the internet survey platform cannot be guaranteed.

If after participating in the survey you would like some support, please contact the research team or any of the following services for assistance:

- Your GP;
- beyondblue: <http://www.beyondblue.org.au/> or 1300 22 4636;
- Lifeline Australia: <https://www.lifeline.org.au/> or 13 11 14;
- MensLine Australia: <https://www.mensline.org.au/> or 1300 78 99 78

Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. You may cease the survey at any time prior to pressing the submission button. Once you have submitted the completed survey you cannot withdraw your responses because they are anonymous and therefore it is not possible to identify your particular responses.

As your participation is anonymous your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with the University of South Australia.

What will happen to information about me?

All anonymous surveys will be stored electronically on a password protected UniSA server, in a locked office at UniSA, City East Campus, and will only be accessed by the research team. The anonymous survey responses will be analysed collectively and not individually. Your information will only be used for the purpose of this research project. Once the project is complete, all electronic and hard copy data will be stored in a locked compactus at UniSA, City East Campus, for five years, after which it will be destroyed.

Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the University of South Australia as required by the Australian government research requirements, specified in the National Statement on Ethical Conduct in Human Research (2007 - updated 2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact Heather McIntyre: E: Heather.McIntyre@unisa.edu.au; T: 8302 1132.

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, please contact the University of South Australia Human Research Ethics Committee: E: humanethics@unisa.edu.au; T: 08 8302 6330

Research Team:

Name	Organisation	Telephone	Email
Ms Heather McIntyre	UniSA	8302 1132	Heather.McIntyre@unisa.edu.au
Professor Nicholas Procter	UniSA	8302 2148	Nicholas.Procter@unisa.edu.au
Dr Mark Loughhead	UniSA	8312 0267	Mark.Loughhead@unisa.edu.au
Dr Laura Hayes	MIND Australia		Laura.Hayes@mindaustalia.org.au

SURVEY CONSENT FORM

This project has been approved by the University of South Australia's Human Research Ethics Committee. If you have any ethical concerns about the project or questions about your rights as a participant please contact the Executive Officer of the University of South Australia Human Research Ethics Committee, Tel: +61 8 83026330; Email: humanethics@unisa.edu.au.

SECTION 1: CONTACT AND PROJECT DETAILS

Researcher's Full Name	Ms Heather McIntyre
Contact Details	Tel: +61 8 8302 1132; Email: Heather.McIntyre@unisa.edu.au
Project Number	203626
Project Title	<i>NDIS and the lived experience of psychosocial disability for people presenting to the emergency department: A mixed methods co-enquiry study</i>

SECTION 2: CERTIFICATION

Participant Certification

In signing this form, I confirm that:

- I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me. I understand and agree to take part.
- I understand the purpose of the research project and my involvement in it.
- I understand that I may not directly benefit from taking part in this study.
- I understand the potential risks associated with taking part in this study.
- I understand that I can withdraw from the study at any time prior to submitting my survey responses and that will not affect my status now or in the future.
- I understand that I cannot withdraw my survey responses after I have submitted the survey as my responses are anonymous and cannot be identified.
- I confirm that I am over 18 years of age.
- I understand I can enter a survey draw where five participants will receive a \$50 EFTPOS card.
- I understand that while information gained during the project may be published, I will not be identified, and my personal results will remain confidential.
- I understand that during the project, the survey data will be stored electronically on a password protected UniSA server, and in hard-copy in a locked office at UniSA, City East Campus, and will only be accessed by the research team. Once the project is complete, all electronic and hard copy data will be stored in a locked compactus at UniSA, City East Campus, for five years, after which it will be destroyed.

I consent. ☐