



Participant Information Sheet/Consent Form

Title: NDIS Participants with Primary Psychosocial Disabilities:
Investigating their formal supports following a life-limiting diagnosis

Ethics Number: Project No 5134

Project Sponsor: Flinders University

Principal Investigator: Ms Kathy Boschen

Associate Investigators: Professor Sharon Lawn, Dr Caroline Phelan

Location: Flinders University

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called "*NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis*".

We would like to understand National Disability Insurance Scheme (NDIS) Participants with primary psychosocial disabilities who receive life-limiting diagnoses and investigate the NDIS' ability to support NDIS Participants as their illness progresses, particularly

- The support received from their formal service systems once diagnosed with a life-limiting condition.
- Is support received equitable to the experience of non-NDIS Participants with a severe and persistent mental illness and/or other Australians without a pre-existing severe and persistent mental illness?
- Is the support received seamless between systems, both their existing NDIS and mainstream supports?

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

This research seeks to explore and report on the experiences of NDIS Participants with primary psychosocial disabilities and investigate the NDIS' ability to support NDIS Participants once they receive life-limiting diagnoses. There is potential for this research is to identify systemic issues and, if required, inform a framework to improve experiences of NDIS Participants with primary psychosocial disabilities and life-limiting conditions. Further, this research could inform future studies into the experiences of the NDIS Participants of all disability types and life-limiting diagnoses and Australians with severe and persistent mental illnesses that do not receive support from the NDIS.

This research has been initiated by Ms Kathy Boschen, a PhD Candidate at Flinders University under the supervision of Professor Sharon Lawn of the College of Medicine and Public Health and Dr Caroline Phelan of the College of Nursing and Health Sciences (Research Centre of Palliative Care, Death and Dying).

3 What does participation in this research involve?

Procedures

You have been approached as a Mainstream Mental Health Clinician. People willing to participate in the study and who met the inclusion criteria will be provided with a participant information and consent form for consideration.

Participation in this study involves taking part in a single interview of about 30 – 45 minutes at a place and time of your choosing. The interview will examine the supports and services either received or expectations around types of funded support that an NDIS Participant with a primary psychosocial disability and a life-limiting condition would expect to receive.

The audio-recording of the interview will be transcribed and you will be offered the opportunity to review the transcript review for accuracy. If you choose to review a summary or transcript, you will be contacted once more to confirm whether you wish to modify any information on the summary or transcript. This is optional.

Bias

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids persons responsible/participants jumping to conclusions. There are no costs associated with participating in this research project, nor will you be paid.

4 Other relevant information about the research project

The research seeks to understand perceived benefits, issues, and gaps in service provision for NDIS Participants with a primary psychosocial disability within the following research cohorts:

1. NDIS Participants with primary psychosocial disabilities.
2. Informal supports of NDIS Participants with primary psychosocial disabilities.
3. NDIA Planners and Local Area Coordinators.
4. Mainstream Mental Health Providers
5. Palliative Care providers,
6. NDIS Providers.

These interviews will inform the development of a larger on-line survey to understand these experiences across Australia.

This PhD Research Project will be monitored by Professor Sharon Lawn and Dr Caroline Phelan from Flinders University.

5 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. If you decide to take part and later change your mind, you may withdraw within a fortnight of the interview, data after this point will have been submerged into the research. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your participation in this study shall not affect any other right you may have to compensation under common law. If you do not wish to participate, your employment will not be affected in any way.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include the identification of systemic issues. It could inform a framework to improve the experiences of NDIS Participants with primary psychosocial disabilities and life-limiting conditions. Further, this research could inform future studies into the experiences of the NDIS Participants of all disability types and Australians with severe and persistent mental illnesses that do not receive support from the NDIS.

7 What are the possible risks and disadvantages of taking part?

Risks:

The study will comply with Flinders University policy regarding confidentiality. Nothing that could identify you will be made public and your name and contact details will be kept in a separate password-protected computer file away from any data that you supply. If you feel any distress from participation in this study, . If this occurs, you may withdraw from this study if you wish, and your employment will not be affected in any way. By participating in this study, you do not give up any of your legal rights.

If you become upset or distressed as a result of your participation in the research, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research project team. Additionally, you can access 24/7 mental health support by contacting Lifeline on 13 11 14, www.lifeline.org.au.

8 What if I withdraw from this research project?

If you do consent to taking part, you may withdraw within a fortnight of the interview, data after this point will have been submerged into the research. If you decide to withdraw from this study, please contact the research team as soon as possible. All data and identifying information will be destroyed. Withdrawing from this research will not impact your employment.

9 What happens when the research project ends?

At the end of your participation in the study, you will (continue your employment as usual.

Outcomes:

If you would like a summary of the study results, please let the person who conducts your interview know.

Part 2 How is the research project being conducted?

10 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. You will be identified by a pseudonym and participant number, not your actual name.

Information required for the study will be entered into an electronic database on a password protected computer. Data will remain linked to a unique code number but without other details to identify you. All of your collected information will be kept by Flinders University for at least 7 years after the end of the study. Only members of the research team will have access to this data. After the 7-year period your identifying information will be destroyed.

Use of information:

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

Privacy:

Under Australian privacy law all information collected about you must be kept confidential, unless you agree to it being released. If you consent to take part in this study, the data collected for the study will be looked at by the research team and authorised persons from Flinders University. They may also be looked at by representatives of regulatory authorities to check that the study is being carried out correctly. All these people will have a duty of confidentiality to you as a research participant and no information that could identify you will be given to anyone else.

Publications:

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. No actual participant names will be used in presentation of results. However, you should note that as the number of participants involved in the study is small, it is possible that someone may still be able to identify you.

11 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

If this occurs, you may withdraw from this study if you wish. By participating in this study, you do not give up any of your legal rights.

12 Who is organising and funding the research?

This research project is being conducted by PhD Candidate Ms Kathy Boschen under the supervision of Professor Sharon Lawn and Dr Caroline Phelan. It has been funded by the Flinders University Research by Higher Degree Program of the College of Medicine and Public Health.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

13 Who has reviewed the research project?

The study has been approved by the Flinders University Human Research Ethics Committee. If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may also contact the Flinders University Human Research Ethics Team human.researchethics@flinders.edu.au or telephone 8201 2543 .

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

14 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 may contact.

Research contact person

Name	<i>Kathy Boschen</i>
Position	<i>PhD Candidate</i>
Telephone	<i>0401 187 582</i>
Email	kathy.boschen@flinders.edu.au

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, then you may contact:

Complaints contact person

Name	Professor Sharon Lawn
Position	Professor – College of Medicine and Public Health PhD Supervisor
Telephone	0459 098 772
Email	Sharon.lawn@flinders.edu.au

Consent Form - *Adult providing own consent*

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Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____	
Signature _____	Date _____

Declaration by Researcher[†]

I have given a verbal explanation of the research project; its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher [†] (please print) _____	
Signature _____	Date _____

[†]An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature