Plain Language Information Statement

Participant Group 3

**Date:**

**Full Project Title:** Accounts of acceptance, coping and wellbeing from people with a neurocognitive disorder

**Project Number:** 2024041601

**Principal Researcher:**

Dr James Donnelly (Senior Clinical Psychologist / Senior Lecturer)

james.donnelly@cairnmillar.org.au

(03) 9813 3400

**Student Researcher:**

Emmaline Coote

14325@cairnmillar.edu.au

**To Participant:**

This Plain Language Information Statement contains information about the research project. Its purpose is to explain to you the procedures involved in this project so that you can make a fully informed decision regarding your participation.

**Why is this research being conducted?**

We are studying how people with neurocognitive impairment (NCI) cope with their challenges. We are particularly interested in the role of acceptance and the ways people cope with the effects of their illness. Our goal is to understand how acceptance and coping styles relate to the wellbeing of people with NCI. We are also asking partners/carers of those with NCI to report on the level of disability they observe.

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**Who can participate in the study?**

You have been nominated to be involved in this study by (Name of Participant). We want to involve partners and caregivers to understand the impact of NCI on daily life for the person with NCI from an alternative perspective. Your participation is voluntary, and you may withdraw from the study with no negative consequences.

**What does participation involve?**

If you consent to participate in this study, you will find a link below to a short questionnaire. You must be proficient in English to complete the online questionnaire we are asking you to complete. An example question is, “In the last 30 days, how much difficulty did your relative have in concentrating on doing something for ten minutes?” The questionnaire should take approximately 10-15 minutes to complete.

**What will happen to the information I provide?**

The data collected will be secured on a password protected computer with access limited to the researchers and staff involved in long-term data storage. The research findings will be presented as a thesis and potentially in journal articles or as conference papers. The data will be given a unique participant ID and stored separately from personal and contact information to ensure participant confidentiality is protected. Data will be stored for 5 years after publication of the thesis or after other papers which arise from the research are published. The de-identified data generated in this study may be used by other investigators only with permission of the current investigators.

**Possible benefits**

You won't receive any immediate benefits, but you will have a chance to contribute to our understanding of how level of disability affects coping in those with NCI. Since there is not a lot of research on these topics for people with NCI, we hope this study will help us learn from your input and improve support for them. By understanding how individuals with NCI see acceptance and coping, and the effects of disability, we can better support their wellbeing in the future.

**Possible risks**

We do not anticipate any risks from completing the survey, however, if you have concerns because of participating in the study, you can seek help by accessing helplines like Beyond Blue and Lifeline, which offer 24/7 support.

This study has been approved by the Human Research Ethics Committee at The Cairnmillar Institute (approval # ) and will comply with the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council of Australia, 2023).

**Who can I contact if I have any questions?**

If you would like further information or have any concerns regarding this project, please contact the investigators (see contact details provided above). If you wish to withdraw your participation at any point through the process, please contact either of the named researchers above.

If you have any concerns or complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may also contact the Secretary to the Human Research Ethics Committee. Please ensure to include the project name, project number and the name of the Principal Researcher in any correspondence when contacting the Secretary of HREC. (You can find these details at the top of this document).

The contact details can be found below:

Secretary to the HREC
The Cairnmillar Institute

391-393 Tooronga Road
Hawthorn East VIC 3123
Phone: 03 9813 3400

Email: hrec@cairnmillar.edu.au

**If I agree to participate, how do I get started?**

If you would like to be involved in this research study, please read the consent form below and proceed to the questionnaire.

Consent Form

I have been asked to participate in a Cairnmillar Institute research project detailed above and agree with the following statements:

[ ]  I have read and understood the Plain Language Information Statement provided to me by the researchers and consent to participate in the research project

[ ]  I understand my participation is completely voluntary

[ ]  I understand I am free to withdraw from the study at any point

[ ]  I consent for my data to be used as outlined in the Plain Language Information Statement

**By clicking on the link below and completing the survey, your consent will be assumed.**

