School of Psychological Sciences
Faculty of Medicine, Health and Human Sciences
MACQUARIE UNIVERSITY, NSW 2109

Human Research Ethics Committee

INFORMATION STATEMENT AND CONSENT FORM

HREC Project Number:	19425
Project Title:	Understanding the Experiences of Young Adults with Chronic Health Conditions: Challenges, Treatment Needs, and Barriers to Psychological Care
Chief Investigator:	Professor Blake Dear

What is the purpose of this research?

This study aims to understand the challenges young adults face when living with a chronic physical health condition. We're especially interested in how these conditions impact mental health, functioning, and how people engage with psychological support. Your feedback will help guide future development of mental health programs designed specifically for young adults.

What does the study participation involve?

To be eligible to participate, you must be:

- Aged 18 to 29 years old
- Currently living with a chronic physical health condition (lasting at least six months) that has been previously or is currently being managed by a healthcare professional
- Can read and write in English

If you choose to take part, after reading this information and consent form, you will be invited to provide your consent online. You will not be able to access the survey until after consent is provided.

Once consent is given, you will complete a 30-minute online survey via your own device, in your own time. As part of this survey, you will be asked about your health condition(s), mood, functioning, experiences with healthcare, and your preferences for mental health support.

Participants who complete the full survey will have the option to enter a prize draw to win one of 4 gift cards valued at $50.

There are no costs associated with participating in this research. This is an online-only study with no follow-up. You will not be contacted after participation unless you choose to opt in, at the end of the survey, to receive a plain-language summary of the study results or to be contacted about future related research (e.g., studies involving young adults with chronic conditions such as focus groups or clinical trials).

Who is conducting the study?

This study is being conducted to meet the requirements for the degree of Doctor of Philosophy (PhD) of Nicole Harte, under the supervision of Professor Blake Dear (blake.dear@mq.edu.au) and Dr Joanne Dudeney (joanne.dudeney@mq.edu.au), from the School of Psychological Sciences, Macquarie University.

Do I have to participate?

Participation in this study is completely voluntary. You are under no obligation to take part.

If you do choose to take part, you will be asked to agree to the terms outlined in this Participant Information and Consent Form by indicating your consent online. You are free to withdraw from the study at any time, without needing to give a reason. However, to be eligible for the prize draw, you will need to complete the full survey. Please note, it will not be possible to withdraw your responses once the survey is submitted as the data is anonymous and cannot be linked back to individual participants.

We ask that, if you choose to participate, you complete the survey honestly and carefully. Your responses are important and will help improve support for young adults living with chronic health conditions.

As a research participant you are responsible for:

- Completely reading information and consent forms
- Carefully weighing the risks and benefits of participation
- Knowing when, where, and for how long participation is required
- Talking to the researcher when concerns arise
- Fulfilling the responsibilities as described in the information and consent forms.

If you withdraw due to distress or any other adverse event, you are encouraged to contact the research the researcher using the details provided in this form.

What are the possible benefits of participating?

We cannot guarantee or promise that you will receive any benefits from this research. However, your responses will contribute to a better understanding of how chronic health conditions affect young adults. These insights can inform the development of more accessible and relevant psychological support services for this age group, with the potential to benefit others in the future.

What are the possible risks and disadvantages of taking part?

The questionnaires are very unlikely to cause any risk to participants. However, some of the survey questions relate to potentially sensitive topics such as mood and stress. While these topics are important for understanding your experiences, they may cause mild discomfort for some participants.

If you become distressed as a result of participating in this research, we encourage you to contact one of the support services listed below. These are free and confidential:

Available support services

Lifeline	p: 13 11 14
Suicide 24/7 callback hotline	p: 1300 659 467
ReachOut	e. www.reachout.com
Beyond Blue	e. www.beyondblue.org.au p: 1300 22 4636

You may also choose to speak with your General Practitioner (GP) or regular healthcare provider, who can offer support and referrals, as required.

What will happen to information about me?

All information gathered during the study is confidential, except as required by law. All survey responses will be collected anonymously, with no identifying information attached to your data. You won't be asked for your name or any identifying details. Please avoid including personal information any free-text responses. Any identifying content added by accident will be removed before data storage and analysis.

If you provide your name and email to enter the prize draw or to opt in to receive a summary of the completed study results or to be contacted for future research, this information will be collected separately and will not be linked to your survey responses.

All anonymous data will be securely stored and backed up on Macquarie University servers, including the Macquarie University Research Data Repository, in accordance with Macquarie University's research data management policies.

The anonymous data gathered during this study will not be made publicly available. However, it may be shared with other approved researchers for future, unspecified research projects, subject to a formal access request, review by the Chief Investigator, and approval from a Human Research Ethics Committee. All shared data will remain anonymous, and researchers must agree to strict terms of use.

It is anticipated that the results of this research will be published in academic journals and presented at conferences. In all publications and presentations, data remains anonymous.

If you have any questions, complaints, or would like more information about this research project or your participation, you can contact Nicole Harte (nicole.harte@hdr.mq.edu.au).

Research contact person

Name	*Nicole Harte*
Position	*Co-Investigator & PhD Candidate*
Email	*nicole.harte@hdr.mq.edu.au*

Consent to participate

I have read and understand the information above. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence.

Signed: _____

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any concerns or complaints regarding any ethical issues related to your participation, or general questions about being a research participant, please contact:

Complaints contact person:

Position	*Director, Research Ethics & Integrity*
Telephone	*+61 2 9850 7854*
Email	*ethics@mq.edu.au*

Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.