



PARTICIPANT INFORMATION AND CONSENT FORM

HREC Project Number: 5201700320

Research Project Title: MQ-MINDS pilot cohort study

Chief Investigator: Dr Reidar P. Lystad

You are invited to take part in this research project, the **MQ-MINDS pilot cohort study**, because you graduated from Macquarie University in 2018. This study aims to pilot the establishment of a cohort of Macquarie University graduates that would shape our understanding of career opportunities and life experiences of graduates.

This Participant Information and Consent Form tells you about the research project, and what is involved. Before you decide whether you wish to participate in this study, it is important for you to understand why the research is occurring and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

If you decide you want to take part in this research project, you will be asked to confirm that you consent to participate. By confirming you are telling us that you:

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

1. What is the purpose of this research?

Throughout young people's lives there are many different events and factors that can have an impact on their life course. Education, changes in employment, different lived experiences, and influences from cultural and socioeconomic circumstances can all have pivotal roles. The period when young people emerge into adulthood is thought to be a distinct period that often include major life events, transitions, and expectations. Yet, none of the existing cohort studies in Australia focus on young people as they emerge into adulthood. This study aims to pilot the establishment of a prospective cohort of Macquarie University graduates that would be a long-term resource to shape our understanding of how various factors affect health and wellbeing of young people as they emerge into adulthood.

2. Why are you inviting me to participate in this research?

You are invited to participate in this study because you graduated from Macquarie University in 2018. All 2018 Macquarie University graduates are invited to participate in this research.

3. What does participation in this research involve?

If you decide to take part in this research project, you will be asked to:

- Confirm that you consent to participate
- Register your contact details on the MQ-MINDS project's secure website
- Complete an online baseline survey
- Complete an online follow-up survey 12 months later

The baseline and follow-up surveys each take approximately 40 minutes to complete and comprise questions about basic demographic details, employment and job satisfaction, physical activity and sedentary behavior, physical and emotional health and wellbeing (e.g. general and social anxiety), social connectedness and support, recent injuries, health behavior (e.g. smoking, alcohol, illicit drug use, and safe sex), recent major life events, carer activities, and social media use.

In addition, you will also be asked to provide consent to having your survey responses linked to your health records, including ambulance, emergency department, hospitalisation, cancer registry and mortality records in NSW, during 1 January 2017 to 30 September 2019.

4. What does it mean to provide consent to using my health information?

The NSW Ministry of Health and Cancer Institute NSW use personal and health information extracted from health records to run the health system. The health information exists in a number of NSW and Commonwealth administrative datasets, from which identifiers have been removed and replaced by a code to ensure your personal privacy is protected. However, it remains possible to re-identify a specific individual by using the code.

By supporting this research study, you are agreeing to the use of your health information as held in the administrative databases that have come from your health records. On behalf of the research team, the Centre for Health Record Linkage will link your health information from the following sources:

- Public and private hospitals, emergency departments, ambulance services, and death registry records held by the NSW Ministry of Health.
- NSW cancer registries

After the linkage, the health information provided to the research team will be in a form that will not identify you. Any health information used from these data sources are managed completely confidentially and are used only for the purpose of the research as described for this study. With your agreement, your health information (as drawn from your health records into the administrative datasets listed above) will be included in the linked health information.

The linkage of health information for this research project is subject to the approval of the NSW Population & Health Services Research Ethics Committee.

5. To participate in this research, do I have to consent to linking my health information?

No. If you want to **opt-out** of having your health information linked to your survey responses, there is an option to indicate this choice on the consent form by selecting the box for opt-out.

6. 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 are free to withdraw from the project at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with the researchers or Macquarie University.

7. What are the possible benefits of taking part?

There will be no clear benefit to you from your participation in this research, but we hope that it may improve the health and wellbeing of young people emerging into adulthood in the future. You will not receive any payment for your involvement in the research.

8. What are the possible risks and disadvantages of taking part?

Although it is not envisaged that any negative consequences will occur, there is a possibility of you feeling that some of the questions we ask are stressful or upsetting. If you do not wish to answer a particular question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, you are encouraged to contact **Lifeline** on 131 114 or **beyondblue** on 1300 22 4636 at any time.

For the linking of your health information there is a low risk to your privacy because personal information (e.g. name, home address, and date of birth) is used in the record linkage process. This risk is minimised by separating the processes of record linkage and data analysis. The record linkage only uses personal information. At the time of analysis a unique personal identification number will replace your personal information.

The linked health information provided to the researchers will only contain your anonymised identification numbers and health information but no names, dates of birth or home addresses. All privacy measures have been put in place to ensure that the confidentiality of your personal and health information are maintained, including removal of identifying information, the use of unique study numbers and adherence to strict guidelines regarding data transfer, storage and access.

9. What if I want to withdraw from this research project?

If you do consent to participate, you may withdraw at any time without having to provide a reason. Please be assured that if you withdraw, it will not affect your relationship with the researchers or Macquarie University. If you decide to withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results.

10. What will happen to information about me?

By agreeing to participate in this research 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. The linked health information as provided by the NSW Ministry of Health and Cancer Institute NSW will not be shared beyond the research team.

In order for the wider community to benefit from the research, we plan to publish and/or present the results of this research project in a variety of forums. We will ensure that in any publication and/or presentation, information will be presented in a non-identified and summary form, so that you or anyone else cannot be identified.

Any information obtained during the research study may be subject to inspection (for the purpose of verifying the procedures and the data) by relevant authorities. By consenting to participate in this research project, you authorise release of, or access to, this confidential information to the relevant research personnel and regulatory authorities, or as required by law.

The information collected for this research will be retained for 5 years after the most recent publication or presentation, and will be destroyed at the completion of this data retention period.

11. Who is organising and funding the research?

This research is being conducted by:

- Dr Reidar P. Lystad, Macquarie University
- Dr Lorna Peters, Macquarie University
- Dr Melissa Johnstone, Macquarie University
- Dr Louise Ellis, Macquarie University
- Associate Professor Rebecca Mitchell, Macquarie University
- Professor Jeffrey Braithwaite, Macquarie University
- Associate Professor Viviana Wuthrich, Macquarie University
- Professor Janaki Amin, Macquarie University
- Dr Cate Cameron, Jamieson Trauma Institute, Queensland Health

This research is being funded by Macquarie University.

12. Further information and who to contact

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 the research contact person:

Name	Dr Reidar P. Lystad
Position	Postdoctoral Research Fellow
Telephone	+61 2 9850 2464
Email	reidar.lystad@mq.edu.au

13. What if I have a complaint?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) at Macquarie University.

If you have any concerns or 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 the HREC that approved this study:

HREC name	Macquarie University Human Research Ethics Committee
Telephone	+61 2 9850 7854
Email	ethics@mq.edu.au

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.

Thank you for taking the time to consider this study.

If you wish to take part in it, please provide your consent below,
and download a copy of this Participant Information and Consent Form to keep.