



In partnership with our community



THE UNIVERSITY OF
NEWCASTLE
AUSTRALIA



Hunter New England
Local Health District

From:

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Regarding Research Project: **Hunter Medical Research Institute Health Pulse Survey**
Document version 1 dated 03/03/25

Participant Information Statement

Dear Potential Participant,

You are invited to take part in the research project noted above which is being conducted by researchers from the Hunter Medical Research Institute (HMRI).

The information below provides more detail about the study and how you can participate if you choose to do so.

1. What is the research study about?

The purpose of the research is to assist HMRI, Australia's largest regional medical institute, with identifying what the biggest health issues facing our region are. As part of this process, we are talking to a range of people including those involved in health and medical research, healthcare providers, policymakers, and the community to understand what matters most to them. The voices of our community members are critical to this process. The information provided will help guide our research priorities and allow us to turn the concerns of our community into real world health solutions. Community involvement will ensure that the research we prioritise is relevant to, and meet the needs of, our community.

2. Who is conducting the research?

This research is being conducted by researchers from HMRI. Specifically, this project is being led by HMRI Institute Director Professor Frances Kay-Lambkin and Research Project Manager, Associate Professor Melissa Harris.

3. Who can participate in the research?

People who are from the Hunter New England region and are aged 16 years and over are eligible to participate in this study. With permission from a parent or guardian, children aged 13-15 years are also eligible to participate. If you have already completed a Health Pulse survey for HMRI through another avenue, are a HMRI affiliate researcher or Hunter New England health service provider, you are not eligible to complete this community survey.

4. What does participation involve?

If you choose to take part, you will be asked to fill out a short 5-minute anonymous survey. If you are aged 16 years and over, you will have several ways to complete the survey. You can complete:

1. an **online version of the survey** by clicking on the link provided in the email you received or by scanning the QR on the recruitment posters or the FAQ document at face-to-face events.
2. a **paper version of the survey** available at face-to-face events.

If you are aged 13-15 years, as you will need permission from a parent or guardian to complete the survey, you will only be able to complete a **paper version of the survey** available at face-to-face events.

In the survey we will ask for some basic information about you and then ask for your thoughts on the health issues that matter most to you and your community. After you have completed the survey, we will ask if you'd like to enter a prize draw to win an Apple Series 10 watch. If you say yes, we'll ask for your name and email. You'll also have the option to say if you'd like more information about HMRI, a summary of the research results or to be contacted in the future about other stages of the Health Pulse project. This is completely optional, and saying yes doesn't mean you agree to anything yet. You will be asked for your permission before any future studies.

5. Do you have to take part in this research study?

No. Taking part in this study is completely up to you. If you do not want to participate, you do not have to. Your choice will not affect your current or future relationship with HMRI. If you decide to take part but change your mind later, you can withdraw from the study without giving a reason. Please note that as this survey is anonymous, if you choose to cease participation part way through the online version of the survey your answers up until that point will be retained. Once you have submitted either the online or paper version of the survey, you will not be able to withdraw your answers.

6. What is the benefit of participating in this research?

We cannot promise you any direct benefit from participating in this research, but your input will help shape HMRI's health and medical research priorities. These priorities will have the potential to create positive impacts on the health and wellbeing of our communities. If you complete the Health Pulse survey, you can enter the draw to win an Apple Series 10 watch by completing a separate entry form. More information about the prize draw can be found on [here](#).

7. Are there any risks associated with your participation in this research?

There are no anticipated risks associated with the research activities you have been asked to participate in.

8. How will your information be used?

We have strict procedures to protect your privacy. All personal and survey information collected remains confidential in accordance with the National Health and Medical Research Council ethical guidelines and the Australian 1988 Privacy Act. Any personal information you provide will be securely stored separately from your survey answers on servers, or hosted through cloud computing providers, physically located within Australian borders. These locations will be isolated from the internet by firewalls. Access to any identifiable data (such as names and contact details) will be restricted to members of the research team and those outlined in this information statement, unless you have consented otherwise; or disclosure is required by law for us to comply with our regulatory obligations.

Surveys completed online will be completed through REDCap (Research Electronic Data Capture), a secure web-based database system. REDCap is a purpose-built software application for the conduct and management of medical research surveys and case report forms for clinical trials. The REDCap application is hosted within Australian borders on HMRI secure servers, which are both physically and virtually secured. User authentication is required for logging into REDCap. All database edits and data entries completed by each user (including REDCap Administrators) are logged in the project's audit trail. Surveys completed on paper will be entered into REDCap and saved on HMRI's secure servers. Paper surveys will be stored in locked filing cabinets at HMRI until data entry and analysis is complete, upon which it will be securely destroyed. The de-identified digital data captured from the surveys will be stored in the research database, separate from any participant contact information.

Digital data will be retained securely for a minimum period of five years from the completion of the research project. Information will be managed and stored in accordance with the University of Newcastle's Research Data and Materials Management Guideline or any successor guideline as well as any other applicable University of Newcastle policy provisions.

9. How will information collected by the research team be used?

If you choose to participate, information collected as part of this project will help guide HMRI's research priorities and turn community concerns into real world health solutions. Individual participants will not be identifiable in any of the outputs generated from the research project. It is expected that the de-identified study results may be used in journal articles, reports, conference presentations, seminars and recommendations to government.

Non-identifiable data may be shared with other parties as part of a peer-review process to verify the robustness and integrity of the study, or to contribute to further research and public knowledge. A summary of the research findings will be shared on the HMRI website and through other HMRI media channels. You also have the option to elect to receive a summary of the results.

10. What do you need to do to participate?

Please read this Participant Information Statement in its entirety and be sure you understand all the information provided before you agree to participate.

If there is anything you do not understand, or if you have questions, contact the Research Project Manager, Associate Professor Melissa Harris on (02) 40420621 or HealthPulse@hmri.org.au.

If you would like to participate, please click on the link in your invitation email (or scan the QR code on the provided FAQ document) and complete the online survey. You are encouraged to retain a copy of this document for your reference.

11. Do you need more information?

If you would like more information about this research, please contact the Research Project Manager, Associate Professor Melissa Harris on (02) 40420621 or HealthPulse@hmri.org.au.

Thank you for considering this invitation.

Professor Frances Kay-Lambkin

Associate Professor Melissa Harris

Institute Director
Hunter Medical Research Institute

Research Project Manager
Hunter Medical Research Institute

Concerns about this research

This project has been approved by the University of Newcastle's Human Research ethics Committee, Approval No. H-2025-0108.

If you have concerns about your rights as a participant in this research, or if you have a complaint about the manner in which the research is conducted, please contact the Research Project Manager, Associate Professor Melissa Harris HealthPulse@hmri.org.au.

If you would prefer to contact someone independent of the research project, you can forward your concerns to:

Human Research Ethics Officer
Research and Innovation Services
University of Newcastle
University Drive
Callaghan NSW 2308, Australia
Phone: (02) 4921 6333 Email: Human-Ethics@newcastle.edu.au