

The 2020 New Zealand

Health, Work and Retirement study

INFORMATION SHEET (v B3.0)



*Professor Christine Stephens
(left) and Professor Fiona
Alpass (right)*

What is the New Zealand Health, Work and Retirement study?

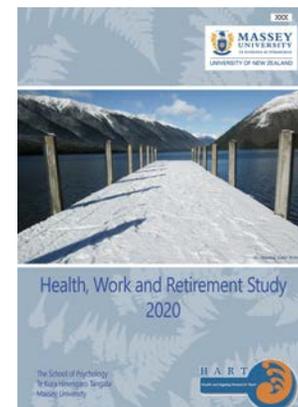
The Health, Work and Retirement study is a study of people aged 55 years and over who are living in New Zealand. The study provides information on issues such as health, work and retirement, which are relevant for research and policy now and into the future. Through this research, New Zealanders can share their experiences of ageing and inform national and international discussions.

The Health, Work and Retirement study began in 2006 and is run by Massey University's Health and Ageing Research Team (HART). The study is led by Professor Christine Stephens and Professor Fiona Alpass from the School of Psychology. To date, over 14,000 New Zealand residents aged 55 and over have been surveyed.

The research has three parts: 1) a health survey; 2) linkage to national health record data, and; 3) linkage to Accident Compensation Corporation (ACC) data. All New Zealand residents have national health records and these include information that is valuable for health research, such as numbers of hospital visits made by a person in a year. Even if this number is zero, this is still important information. Many New Zealanders will also have ACC injury and related health records. Anonymised linkage to these datasets helps us to assess the impact of events such as health care, accidents, and injuries on wellbeing in New Zealand.

Why have I been contacted?

You are invited to participate in the Health, Work and Retirement study. Every two years, the study randomly selects new people aged 55+ from the electoral roll to be surveyed. People who have previously filled out a survey are invited to complete the survey every two years to assess changes, or lack of change, in their circumstances over time. This year, over 4,000 New Zealanders will be surveyed in total. Contacting a large, random sample of the population is important for understanding the range of circumstances experienced by older people in New Zealand. As a token of appreciation, everyone who returns the survey will be entered into a prize draw to win one of four \$50 supermarket vouchers. The first prize will be drawn in October 2020, and every six months until all prizes are allocated.



Linkage to national health and ACC records

With your consent, our study will link your survey responses to records held in national datasets held by the New Zealand Health Information Service (Ministry of Health) and the Accident Compensation Corporation (ACC). Both survey answers and these linked data will be de-identified. This means that no individual can be identified using these data. This data linkage allows the research team to answer a number of important questions regarding health and wellbeing that could not be addressed by either a survey, national health record data or ACC data alone.

With your consent, we would request any injury and related health data held by the ACC. The table below lists the six datasets that we would request from the New Zealand Health Information Service if you consent to participate in the data linkage study:

National Minimum Dataset: Hospital Events	Hospital discharge information, including health diagnosis and event information (e.g., times, dates).
National Non-admitted Patient Collection	Data about events such as outpatient and emergency department visits.
New Zealand Cancer Registry	Register of all primary cancers diagnosed in New Zealand.
Pharmaceutical Collection	Information from pharmacists about subsidised prescriptions.
Mental Health Information Collection	Information on mental health care provided, diagnosis of mental health condition and discharge.
Mortality Collection	Information on causes of death for all deaths registered in New Zealand.

What do I need to do to participate?

Participation involves filling out the enclosed survey and returning it. This should take about 45 minutes. Please also sign the consent form if you consent to the research team obtaining your health records from the New Zealand Health Information Service and your injury and related health data from ACC. You can return the survey and consent form in the freepost envelope supplied. Even if you do not consent to data linkage, you can complete the survey and return it to us. Participating in either part of the study is entirely voluntary.

If you sign and return the consent form, the research team will provide the New Zealand Health Information Service and ACC with your name, your address, and your date of birth. This information is used by these agencies to identify the correct health records. The research team will contact the New Zealand Health Information Service and ACC periodically to update these records. You can withdraw your consent at any time by contacting the HART free phone number **(0800 100 134)** or email the team at hart@massey.ac.nz.

Will my data remain secure and confidential?

All information provided is completely confidential and will be used only for the purposes of health research by approved researchers. It will not be possible to identify individuals in any dataset or publication from the study. We use a unique ID code printed on the top right-hand corner of the survey booklet to identify who has returned the anonymised survey. The research team uses these ID codes to link responses to surveys returned from the same participant over time. Survey responses and other study data are always stored securely and separately from your name and address details.

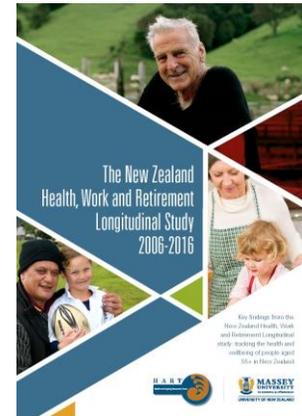
To ensure that national health record and ACC data remain confidential, a confidential data-transference and merging process is used. You can rest assured that:

- Once your national health and ACC records are found and extracted by the relevant agencies, your name will be replaced with a unique ID number.
- This de-identified data will be encrypted and sent via registered courier to the Health and Ageing Research Team (HART) at Massey University. The key to unlock the encrypted dataset will be sent separately via secured email directly to the HART.
- The HART will merge this information with other data provided by you, using your unique ID number. This ensures that your name will always be stored separately to your data, and that both your study data and national health record and ACC data are unable to be directly linked to your name, except by the HART Research Officer as required for study administration purposes.
- The New Zealand Health Information Service and ACC will never have access to your data stored at Massey University.

What are my rights as a participant in this study?

If you decide to participate, you have the right to:

- Decline to answer any particular question;
- Ask any questions about the study or withdraw from the project at any time by calling the HART contact number (**0800 100 134**) or emailing the team at hart@massey.ac.nz;
- Know that the information will be kept strictly confidential and will be used only for health research;
- Know that reports and publications from this study will not identify any individual taking part.



A report on the first ten years of the study is available on the HART website



Research Officer Ms Vicki Beagley

Who can I contact if I have further questions about this study?

You can contact the Health and Ageing Research Team researchers at any time on the free-phone number **(0800 100 134)** or you can email a question to hart@massey.ac.nz. This will put you in contact with Ms Vicki Beagley, who will send your request to the appropriate team member.

We have a website with information for those participating or interested in the study. This site includes a description of the study, together with answers to frequently asked questions. Summary reports of the study findings are available on the website and copies can be mailed to participants on request.

Statement of Ethical Approval

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 20/07. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz

Thank you!

We greatly appreciate your consideration of this invitation and we welcome your participation in the New Zealand Health, Work and Retirement study. Please feel free to contact us if you would like further information or would like to ask any questions about this project.

Free-phone 0800 100 134

Email hart@massey.ac.nz

Website hart.massey.ac.nz/

