

The New Zealand Health, Work & Retirement study

INFORMATION SHEET (v B1.0)

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

The New Zealand Health, Work and Retirement study is a study of persons aged 55 years and over who are living in New Zealand. The study aims to provide information on issues such as health, work, retirement and housing which are relevant to persons in this age group. This research provides New Zealand residents with the opportunity to share their experiences to help inform national and international discussions on these important issues.

The research has two parts: 1) a biennial health survey, and; 2) the linkage of national health record data, held on file by the New Zealand Health Information Service, to other data provided by study participants. All New Zealand residents have national health records and these contain valuable information for health research, such as numbers of hospital emergency room visits made by a person in a year. Even if this number is zero, this is still important information.

The New Zealand Health, Work and Retirement study commenced in 2006 and is an initiative of 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 8,000 New Zealand residents aged 55 and over have been surveyed.

Why have I been contacted by the study?

We would like to invite you to participate in the New Zealand Health, Work and Retirement study. Persons who have previously filled out a questionnaire are re-surveyed every two years to obtain valuable information regarding changes, or lack of change, in their circumstances over time and it is this information across time which makes the HWR study increasingly valuable.

Every two years, the study also randomly selects additional persons aged over 55 from the electoral roll to be surveyed. This year, over 7,400 New Zealand residents will be surveyed to ensure adequate representation of the population over a 10 year follow-up period. By obtaining responses from a large, random sample of the population, the study aims to obtain a good representation of the range of circumstances experienced by all older persons in New Zealand.

Many countries around the world have now developed studies that link health survey data with health records and these studies have allowed researchers to examine important questions. Your contribution to this study would allow the team to answer a number of important health questions which could not be addressed by either a survey or national health record data alone. The current study will allow researchers to examine questions such as what impact hospitalisation might have on older New Zealanders' economic independence and quality of life, and the identification of factors linked to health and healthcare utilisation among New Zealanders.

The table below lists the five datasets that we would request from the New Zealand Health Information Service if you consent to participate in the study:

National Minimum Dataset: Hospital Events	A collection of hospital discharge information, including clinical information (e.g., health diagnosis) and event information (e.g., times, dates).
National Non-admitted Patient Collection	Data about non admitted face-to-face secondary care 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 for subsidised dispensing that has been processed by the HealthPAC General Transaction Processing System (GTPS)
Mental Health Information Collection	Information on mental health care provided, diagnosis of mental health condition, legal status, and discharge.

What do I need to do?

Participating in this study is entirely voluntary. Participation involves filling out the enclosed questionnaire whenever you have some spare time, and returning it with the signed consent form granting permission for the HART to obtain your de-identified health records from *New Zealand Health Information Service*. This would take about 45 minutes in all.

By signing the consent form you are allowing us to provide the New Zealand Health Information Service with the following information that we have on file: (a) your name, (b) your address, and (c) your date of birth. This is the information that the *New Zealand Health Information Service* requires to ensure they access the correct health records for you.

You can return the questionnaire and consent form in the freepost envelope supplied. The questionnaire has a code number at the top of the page for our records which is used to identify incoming mail so that your name can be taken off our reminder mailing list. We also use this code to link the information across surveys, but this is always stored securely and separately from your name and address details.

Will my data remain secure and confidential?

All information provided to researchers is completely confidential, and will be used only for the purposes of health research. It will not be possible to identify individuals in any dataset or report from the study. Your survey will be kept in a locked room and all surveys destroyed five years after the completion of the study. To ensure that your national health record data remains confidential, a strong and confidential data-transference and merging process is used. You can rest assured that:

- Once your national health records are identified and extracted by the New Zealand Health Information Service, they will replace your name with a unique ID number. Once this ID is in place none of the data can be linked back to your name.
- The de-identified national health record data will then be securely encrypted to CD, and the encrypted CD sent via registered courier directly to the Health and Ageing Research Team (HART) at Massey University. The electronic key needed to unlock this encrypted dataset will be sent separately via secured email directly to the HART. Without this electronic key the encrypted CD is not able to be accessed.
- Once the HART receives the national health record dataset and de-codes it with the electronic key, this data will be merged with other data provided by you to the HART using your unique ID number. This ensures that your name is always still stored separately to your data and that both your study data and the national health record data are unable to be directly linked to your name, except by the HART Research Officer.
- The New Zealand Health Information Service will never have access to your data stored at Massey University and only the HART Research Officer will be involved in this data-linkage process.

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 are based on de-identified information and will not identify any individual taking part.

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

You can contact the HART researchers at any time on the HART free-phone number (**0800 100 134**) or you can email a question to hart@massey.ac.nz. This will put you directly in contact with Ms Vicki Beagley who can send your request to the appropriate team member. We have also developed a dedicated website to provide general information for those participating or interested in the study. This site also includes a general description of the study, together with answers to frequently asked questions about the study. Summary reports of the study findings are made available on the Health and Ageing Team website and a hard copy will be mailed to participants on request. You can access this website at: **HART.massey.ac.nz**

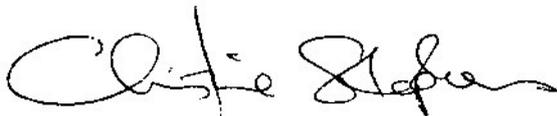
Statement of Ethical Approval

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 15/72. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz.

Thank you!

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

Sincerely

A handwritten signature in black ink, appearing to read 'Christine Stephens', written in a cursive style.

Professor Christine Stephens, on behalf of the *Health & Ageing Research Team* (HART) at Massey University.