

The HART Data-Linkage Project: Information Sheet

All New Zealanders have national health records that are held on file by the *New Zealand Health Information Service* (NZHIS) which is a part of the Ministry of Health. These records contain valuable information for health researchers, such as the number of hospital emergency room or GP clinic visits people make in a year. Many countries around the world have now developed *new* studies that link health survey data with health records. These *new* studies are called ‘Data-Linkage’ studies and they are a powerful tool for answering health-related questions on ageing.

We would like your consent to pair your NZHIS data with your data from our HART studies to develop the **HART Data-Linkage Project**. These combined data would allow us to answer a number of very important health questions which we cannot currently answer using our existing survey data, such as what impact hospitalisation might have on older New Zealanders’ economic independence and quality of life.

Creating a data-linkage between your HART study data and your national health records would help us:

- Understand the key factors linked to health and healthcare utilisation among ageing New Zealanders
- Enhance our ability to answer key questions relevant to the functioning of our health system
- Compare our health trends with data-linked studies from around the world

New Zealand studies using data-linkage

- Growing Up in New Zealand
- New Zealand Survey of Family, Income and Employment – Health

International studies using data-linkage

- Australian Longitudinal Study of Ageing
- Australian 45 & Up Study
- Australian Longitudinal Study on Women’s Health
- Australian Health in Men Study
- English Longitudinal Study on Ageing
- US Health & Retirement Study
- Survey of Health, Ageing & Retirement in Europe
- Canadian Longitudinal Study on Ageing

Do I have to take part in this project?

No. Your participation in the HART Data-Linkage Project is entirely voluntary. You can decline this invitation to participate in this data-linkage and this will not influence your on-going participation in the HART postal survey studies. Furthermore, if you agree to participate in the data-linkage project now you can decide to withdraw at a later date and we will remove you from the project.

What national health records is HART asking to access?

The table below lists the 5 datasets (and the information within them) that we would request from the NZHIS if you consent to take part in this data-linkage project:

New Zealand Health Information Service (NZHIS) Datasets	
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?

If you consent to this data-linkage all you need to do is complete the consent form accompanying this information sheet which is titled '*Consent Form for the Health & Ageing Research Team data linkage project.*' By signing this consent form you are allowing us to provide the NZHIS 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 NZHIS requires to ensure they access the correct health records for you. You only need to sign this consent form once and this will allow us to periodically contact the NZHIS in the future (i.e., approximately every two years) with your details so we can access your up-to—date NZHIS records without having to bother you again to sign another consent form.

Will my HART and NZHIS data still remain secure and confidential?

Your HART study data and your NZHIS health record data will remain absolutely confidential throughout this linkage process. Using protocols developed for data-linkage both in New Zealand and internationally we have developed a strong and confidential data-transference and merging process that ensures your data will remain confidential. You can rest assured that:

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

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/62. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz.

Do I have to consent to this HART Data-Linkage project? If I do consent, what are my rights?

This data-linkage project is voluntary; you do not have to participate if you do not want to. If you do not wish to provide consent for this project then you can simply continue to carry on as a participant in our regular study and this will not in any way prejudice your involvement in future research with HART.

If you do wish to consent your rights are as follows:

- You can withdraw from the project at any time by calling the HART contact number (**0800 100 134**), and withdrawing will not interfere with your right to carry on as a participant in other HART studies;
- Your information will only be used for health research purposes, which includes understanding the impact of health diagnoses and healthcare utilisation on successful ageing in New Zealand, and understanding the long-term health, wealth and social factors that result in different health states and healthcare utilisation as New Zealanders age
- Your consent for HART to access your national health records will continue to be valid for HART research following potential disablement unless this consent is withdrawn by your next of kin;
- Your information will be kept strictly confidential and will be used only for health research;
- Reports and publications from this project and studies based on the linked data will be based on de-identified information and will not identify any individual taking part.

Who can I contact if I want to discuss this request?

You can contact the HART researchers at any time on the HART free-phone number (0800-100-134) or you can email a question using the current email address for the HART studies (hart@massey.ac.nz). This will put you directly in contact with Mr Brendan Stevenson who is the HART research officer managing this data-linkage process.

We greatly appreciate your consideration of this request and we would welcome your participation in the HART Data-Linkage Project. 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



Dr Andy Towers, on behalf of the Massey University Health & Ageing Research Team (HART):

School of Psychology	School of Health & Social Services	School of People, Envir. & Planning
Professor Christine Stephens Assoc. Professor Fiona Alpass Dr Jo Taylor Dr Rachael Pond Mr Brendan Stevenson	Professor Steve La Grow Dr Mary Breheny Dr Polly Yeung Dr Andy Towers	Dr Juliana Mansvelt