

**- Technical Report -
Health, Work and Retirement (HWR)
National Health Data Linkage Project '16:
approach protocol and response**

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This report outlines the rationale, protocol and response rate associated with the 2016 approach for consent to participate in the New Zealand Health, Work & Retirement study national health data linkage project.

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New Zealand Health, Work and Retirement Study National Health Data Linkage Project

Overview of the Health, Work and Retirement study

The New Zealand Health, Work and Retirement (HWR) study is the flagship initiative of Massey University's Health & Ageing Research Team (HART). A core component of the study is a biennial longitudinal survey, assessing experiences of health and wellbeing of older New Zealand adults. Following recruitment of the original HWR cohort in 2006, additional cohorts have been recruited over time to support representation of older age groups and assess the wellbeing of older adults over time. Original and 2016 survey response rates by cohort are presented in [Table 1](#).

Table 1 HWR survey response rate by cohort at recruitment and at 2016 survey

Year cohort recruited	Original approach <i>n</i>	Original response <i>n</i>	Original response %	2016 response <i>n</i>	2016 response %
2006	13045	6661	51.1%	1563	12.0%
2009	4502	1000	22.2%	586	13.0%
2014	2900	774	26.7%	607	20.9%
2016	4298	1272	29.6%	1272	29.6%

Overview of the National Health Data Linkage Project

In 2013, the Health, Work and Retirement study initiated a project to link the collected self-reported survey data with national health record data for participants who provided written informed consent to participate in this new arm of the study. Such linkage projects allow survey studies to address questions such as the impact of hospitalisation on participant outcomes, and the identification of factors linked to health and healthcare utilisation. [Table 2](#) lists the administrative records held by the New Zealand Health Information Service for which participants were approached for consent to link to.

Table 2. Health information databases to be accessed under the HWR national health data-linkage project

Data set	Description
<i>National Minimum Dataset: Hospital Events</i>	A collection of hospital discharge information, including clinical information (e.g., health diagnosis) and event information (e.g., times, dates).
<i>National Non-admitted Patient Collection</i>	Data about non admitted face-to-face secondary care events, such as outpatient and emergency department visits.
<i>New Zealand Cancer Registry</i>	Register of all primary cancers diagnosed in New Zealand.
<i>Pharmaceutical Collection</i>	Information from pharmacists for subsidised dispensing that has been processed by the HealthPAC General Transaction Processing System (GTPS)
<i>Mental Health Information Collection</i>	Information on mental health care provided, diagnosis of mental health condition, legal status, and discharge.

As outlined in the project information sheets, consent indicated that HART researchers may provide the necessary minimum identifiers (name, gender, date of birth) to technicians at the New Zealand Health Information Service in order to identify the participant's National Health Index (NHI) number. The de-identified data would then be matched to records held by Analytical Services (Ministry of Health). Where a successful match could be made and data extracted, data were again stripped of identifying information, encrypted and delivered to the HART.

Approach and response rate 2014-2015

A complete report in the 2014-2015 protocol for national health data linkage consent and associated response rate is provided in the related technical report ¹. Briefly, two approaches for consent to participate in the national health data linkage project were made to participants who were considered active in the study. These included an initial approach in 2014 and a follow-up contact in 2015 sent to new and previously non-responding participants. In each of these approaches, eligible participants were sent an introductory letter, information sheet, a consent form and a return envelope. Active participants in the Health, Work and Retirement study who did not respond to the initial approach for consent in 2014 were approached a second time in 2015. A new cohort recruited to the study in 2014 were approached for consent in 2015. Data from returned consent forms were entered into a database on receipt by the research team and audited to confirm completeness and consent status prior to initiating the data linkage project protocol.

Of the $n = 3770$ participants approached for consent to participate in the data-linkage project between 2014 and 2015, $n = 2691$ responded (71.4%), with $n = 2356$ consenting to participate (consent rate of 62.5%). Rates of consent were somewhat higher participants recruited in 2006 and 2009 (63.8%) who had both participated in the study longer and were approached for consent twice. Those recruited in 2014 were only approached once and displayed lower consent rate (57.3%).

Approach and response rate 2016

It was decided that any newly recruited participant cohorts would be approached for consent to participate in the data linkage project at the same time as they were first approached to participate in the HWR study (i.e., at the time of receiving their first postal survey). As such, the information sheet sent with the HWR postal survey booklet also included all information in the national health data linkage information sheet, and a consent form was also provided to be returned with the postal survey. Further information on the survey protocol can be found in the related technical report². Data from returned consent forms were entered into a database on receipt by the research team and audited to confirm completeness and consent status prior to preparation of this report and initiation of the data linkage project protocol.

As presented in [Table 1](#), $n = 1272$ persons approached to be part of the 2016 cohort returned the HWR survey. Of these, $n = 1187$ (93.3%) returned a completed consent form, indicating consent to participate in the national health data linkage project.

¹ Allen, J. (2016). *Health, Work and Retirement (HWR) National Health Data Linkage Project '14-'15: approach protocol and response*. Technical report for the Health, Work and Retirement Study. Palmerston North: Massey University. Retrieved from <http://www.massey.ac.nz/?tcc5d3501s>

² Allen, J. (2017). *2016 Health, Work and Retirement (HWR) Survey*. Technical report for the Health, Work and Retirement Study. Palmerston North: Massey University. Retrieved from <http://www.massey.ac.nz/?tcc5d3501s>