

-Technical report-  
Health, Work and Retirement (HWR) National  
Health Data Linkage Project 2018: approach  
protocol and response

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This report outlines the rationale, protocol and response rate associated with the 2018 approach for consent to participate in the New Zealand Health, Work and Retirement study national health data linkage project.

## Contents

New Zealand Health, Work and Retirement Study National Health Data Linkage Project .....	2
Overview of the Health, Work and Retirement study .....	2
Overview of the National Health Data Linkage project .....	2
Approach and response rate 2014-2015 .....	3
Approach and response rate 2016-2018 .....	4
Data linkage match rate.....	4

# 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 2018 survey response rates by cohort are presented in Table 1.

Table 1. HWR survey response rate at recruitment and at 2018 survey.

Year cohort recruited	Original approach <i>n</i>	Original response <i>n</i>	Original response %	2018 response <i>n</i>	2018 response %
2006	13045	6661	51.1%	1434	11.0%
2009	4502	1000	22.2%	540	12.0%
2014	2900	774	26.7%	552	19.0%
2016	4298	1272	29.6%	838	19.5%
2018	3596	598	16.6%	598	16.6%

## 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
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.

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 on the 2014-2015 protocol for national health data linkage consent and associated response rate is provided in the related technical report<sup>1</sup>. 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

<sup>1</sup> 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>

2015, n = 2691 responded (71.4%), with n = 2356 consenting to participate (consent rate of 62.5%). Rates of consent were somewhat higher for 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 2016-2018

From 2016 onwards, 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 survey). The first mailout for 2018 refresh participants contained an information sheet containing all information on both the survey and the national health data linkage project, a link to the online version of the survey, and a consent form to be returned in the included pre-paid return envelope. Participants who did not return a consent form or complete the online survey were sent a replacement consent form along with a postal survey in the second mailout 12 weeks later. Further information on the survey protocol can be found in the related technical report<sup>2</sup>. 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, of the n = 3596 persons initially approached to be a part of the 2018 cohort, n = 598 returned a completed HWR survey. Of these, n = 506 (84.62%) also returned a completed consent form, indicating consent to participate in the national health data linkage project.

### Data linkage match rate

All existing participants who had given consent in previous years, and all refresh participants who had returned a completed consent for in 2018 were sent to Analytical Services for matching to the health information databases. Table 3 outlines the match rate for each cohort. Of the N = 4056 who consented to data linkage, a match was identified for n = 4011 (98.89%).

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<sup>2</sup> Phillips, H. (2019). 2018 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>

Table 3. Match vs no match by cohort for consenting participants.

	<b>Match</b>	<b>No match</b>	<b>Total</b>
HWR 2006	1398	5	1403
NZLSA 2010	3	0	3
2009 Retirement planning	360	0	360
2009 NZLSA pilot study	147	0	147
HWR 2014	442	4	446
HWR 2016	1182	9	1191
HWR 2018	479	27	506
	<b>4011</b>	<b>45</b>	<b>4056</b>