-Technical report-
Health, Work and Retirement (HWR) National Health Data Linkage Project 2020: approach protocol and response

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This report outlines the rationale, protocol and response rate associated with the 2020 approach for consent to participate in the New Zealand Health, Work and Retirement study national health data linkage project.

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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 2020 survey response rates by cohort are presented in Table 1.

Table 1. HWR survey response rate at recruitment and at 2020 survey.

Year cohort recruited	Original approach *n*	Original response *n*	Original response %	2020 response *n*	2020 response %
2006	13045	6661	51.1%	1295	9.9%
2009	4502	1000	22.2%	502	11.1%
2014	2900	774	26.7%	523	18.0%
2016	4298	1272	29.6%	754	17.5%
2018	3596	598	16.6%	406	11.3%
2020	3552	871	24.5%	871	24.5%
Total	**31,893**	**11,176**	**35.0%**	**4351**	**13.6%**

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[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

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[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

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 2016-2020

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). Additionally, from 2018 onwards, newly recruited participants will also be approached for consent to link to the national Mortality Collection. The consent rate for each year since 2016 is presented in Table 3.

The first mailout for 2020 refresh participants contained an information sheet containing all information on both the survey and the national health data linkage project, and a consent form to be returned in the included pre-paid return envelope. Participants who did not return a consent form or the 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[2]. Data from returned consent forms were entered into a database on receipt by the research team.

As presented in Table 3, of the n = 3552 persons initially approached to be a part of the 2020 cohort, n = 871 returned a completed HWR survey. Of these, n = 525 (60.3%) also returned a completed consent form, indicating consent to participate in the national health data linkage project.

Table 3. Proportion of participants responding to the 2020 survey who have given written consent for national health data linkage.

Year recruited	**Initial approach *n***	**2020 Survey responses *n***	**Consenting *n* of 2020 responses**	**% of 2020 responses**
2006	13045	1295	1054	81.4%
2009	4502	502	405	80.7%
2014	2900	523	353	67.5%
2016	4298	754	723	95.9%
2018	3596	406	357	87.9%
2020	3552	871	525	60.3%
Total	**31893**	**4351**	**3417**	**78.5%**

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[2] Phillips, H. (2021). 2020 Health, Work and Retirement (HWR) Survey. Technical report for the Health, Work and Retirement Study. Palmerston North: Massey University.

Overall, of the n = 4351 participants who returned a 2020 survey, n = 3417 (78.5%) have provided written consent to national health data linkage.

Mortality data linkage

Minimum identifying information for all participants recruited prior to 2018 who had completed at least one of the previous survey waves and all 2018 and 2020 refresh participants who provided written consent to mortality data linkage at the time of data extraction were sent to Analytical Services for linking to national mortality records. At the time of data extraction, n = 541 refresh participants had given written consent for mortality data linkage. A further n = 56 refresh participants subsequently returned consent forms after this date but were not included in the execution of the mortality data linkage protocol in 2020. Of the n = 12585 records supplied, n = 10498 (83.42%) were matched to an NHI number. Of these, n = 1623 (15.46%) were deceased. The match rates for each cohort are presented in Table 4.

Table 4. Mortality data linkage match rate by year of cohort recruitment to the HWR longitudinal study.

Year cohort recruited	Match	No match	Total
2006	5982	679	6661
2010	545	40	585
2009	1815	160	1974
2014	723	50	773
2016	1179	360	1539
2018	121	391	512
2020	133	408	541
Total	**10498**	**2087**	**12585**