

- Technical Report -
Health, Work and Retirement (HWR) National
Health Data Linkage Project '14-'15: approach
protocol and response

Version 1.0, January 2016

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The Health, Work and Retirement Study

Overview 2006-2014

The New Zealand Health, Work and Retirement (HWR) study is the flagship initiative of Massey University's Health & Ageing Research Team (HART). At the study's centre is the HWR longitudinal survey, a cohort study of older persons in New Zealand which is designed to describe the nature and determinants of health and wellbeing in this population. Other research modes have been undertaken to compliment this core data collection, including repeated face to face cognitive assessment and interviews in 2010 and 2012.

The study commenced in 2006 with the recruitment of the initial HWR cohort, comprised of persons aged 55-70 randomly sampled from the New Zealand electoral roll (Towers, 2007). An over-sample of persons indicated on the roll as being of Māori-descent was undertaken to ensure adequate representation of this important sub-group in the 2006 survey. N = 6,662 New Zealanders responded to the survey (gross response rate of 53%) and around 46% of these initial survey respondents indicated that they were interested in participating in a longitudinal survey cohort and were re-approached for participation in subsequent survey waves.

Since the recruitment of this initial cohort, the HWR survey has been conducted biennially, with an additional off-wave survey of the initial 2006 cohort also conducted in 2013. In 2009 a new sample aged 50-84 was drawn from the electoral role. These potential participants were recruited for the purposes of the Retirement Planning study (RP: Noone, Stephens, & Alpass, 2010) and the New Zealand Longitudinal Study of Ageing (NZSLA) which was conducted in partnership with the Family Centre Social Policy Research Unit (Towers & Stevenson, 2014). The RP study commenced with an off-wave pilot survey in 2009 and this cohort were re-surveyed in 2010, 2012 and 2014. A 2009 pilot cohort were recruited and surveyed ahead of the NZSLA study and were re-surveyed in 2010, 2012 and 2014. The NZSLA cohort were approached for participation in 2010 and re-surveyed in 2012, at which point the study of the NZSLA cohort concluded. Most recently, a 2014 'refresh' cohort was recruited as part of a move to a steady state design. A summary of the survey waves by year and cohort surveyed is provided in Table 1. For a more detailed reporting of methods, mortality and attrition in the HWR study 2006-2014, see Towers et al. (2015).

Table 1 HWR survey waves by cohort 2006-2014¹

Cohort	2006 survey	2008 survey	2009 survey	2010 survey	2010 F2F interviews	2012 survey	2012 F2F interviews	2013 survey	2014 survey
HWR	✓	✓	X	✓	✓	✓	✓	✓	✓
RP	-	-	✓	✓	✓	✓	✓	X	✓
NZSLA Pilot *	-	-	✓	✓	✓	✓	✓	X	✓
NZSLA	-	-	-	✓	✓	✓	✓	X	X
2014 HWR Refresh	-	-	-	-	-	-	-	-	✓

¹ Table notes: HWR 'Health, Work and Retirement'; RP 'Retirement Planning'; NZSLA 'New Zealand Longitudinal Study of Ageing'; ✓ = cohort was surveyed; X = cohort was not surveyed.

The retirement planning cohort completed a different survey in 2009 which included core measures of SF-12, ELSI, demographics, employment, and income. This cohort was invited to opt-in to the longitudinal cohort study from 2010 onwards.

The Health, Work and Retirement Study National Health Data Linkage Project 2014-2015

Many countries have now developed studies that link health survey data with health records to examine important questions which could not be addressed by either a survey or national health record data alone. The Health, Work and Retirement study has initiated a data linkage project to address 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. In this protocol, active participants were approached for consent for their data, provided as part of the HWR study, to be matched to health information records held by the New Zealand Health Information Service, including databases in Table 1.

Table 1. 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.

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). A report on the method used by the NZHIS to match participant minimum identifying information to NIH numbers will follow the completion of this project phase.

To date (January, 2016) active participants in the Health, Work and Retirement longitudinal study who were recruited prior to 2014 have been approached for consent to data linkage twice, with participants who did not respond to the consent process in 2014 approached a second time in 2015. A new '2014 refresh' cohort recruited to the survey in 2014 has been approached once. It is intended that all future recruits to the Health, Work and Retirement study will be asked for their consent to participate in this project. The following sections outline the approach and consent protocols used in the study 2014-2015 and the resultant response rates.

Materials were prepared and clearance was obtained from the Massey University Human Ethics Committee (Southern A Applications – 13/62) and the Health & Disability Ethics Committee (Ethics Ref: 14/CEN/79). The initial data linkage approach was funded by the Massey University College of Health and the second approach by the Massey University College of Humanities and Social Sciences. The study is overseen by Prof Christine Stephens and Prof Fiona Alpass. Mr Brendan Stevenson was the project Research Officer (November 2011 – December 2014) and Dr Joanne Allen was the project Research Officer (April 2015 – current).

Participants

The first approach (July, 2014) was made to existing participants recruited in either the 2006 or 2010 recruitment waves who remained active participants in the HWR study at the time of the 2014 survey mail out (i.e., had not withdrawn, been lost to contact or were known to be deceased). In this approach, participants were asked *only* whether they would provide *positive* consent to participate in the data linkage project. No follow-up contact was made.

The second approach (July-September, 2015) was made to existing participants who: **1)** did not respond to the first data linkage consent approach (i.e., had not responded to the first approach in 2014); **2)** had not refused data linkage through other modes, such as by mail or over the phone; and **3)** remained active participants

following the 2014 survey (i.e., responded to the 2014 survey, had not since withdrawn from the study or known to be deceased from either national mortality statistics² or through verbal notification to the study)³. Additionally, a new cohort of participants recruited as part of the '2014 refresh' cohort and remained active (i.e., responded to the 2014 survey and had not withdrawn nor were known to be deceased) were also approached for participation in the data linkage project at this time. In this second approach, participants were given the option to indicate either *positive* or *negative* consent to participation in the data linkage project. Where contact information was available, participants were followed up by telephone.

Method

Table 2 presents an overview of contacts with participants as part of the Health, Work and Retirement Study protocol 2014-2015. In both the first and second approach for data linkage consent, participants were sent a packet containing an introductory letter, an information sheet, a consent form and a reply paid envelope via New Zealand post. In the first approach (2014), participants were asked to indicate their consent for data linkage. No follow-up contact was made with participants. In the second approach (2015), the consent form was amended and participants were asked to reply on the consent form either 'yes' or 'no' to data linkage. The second approach was mailed-out to participants in a staggered fashion to allow for timely follow up of non-responding participants by the research team: batches of n = 200 packets were sent every week for 12 weeks. Follow-up phone calls were made to participants who had not responded within 3 weeks of the packet being posted. Only one follow-up call resulting in contact with the person was made to each participant and only two follow-up calls resulting in non-contact with a participant were made. Participants were re-sent the approach documents if needed following the phone contact. If the participant did not want to participate in the data linkage project, this response was also accepted over the phone whereas a signed consent form was necessary to indicate positive consent.

Table 2. Overview of contacts with Health, Work and Retirement study participants 2014-2015

Date	Contact description
July '14	First data linkage approach (to active existing cohort participants)
Existing cohort: Oct '14	2014 Survey
Refresh cohort: Dec '14	
Existing cohort: Dec '14	Survey reminder postcard
Refresh cohort: Mar '15	
Mar '15	Telephone reminder to return the survey (existing cohort participants)
May '15	Newsletter (active existing cohort participants and active 'refresh' cohort participants)
July '15-October '15	Second data linkage approach (to active existing cohort participants who did not respond to the first approach and active 'refresh' cohort participants). Staggered mail out with telephone follow-up after 3 weeks for all non-responding participants.

Note: 'Refresh' refers to a new sample of persons aged 55-65 undertaken in 2014. Participants recruited prior to 2014 are referred to as 'existing'.

Response rates

As presented in Table 3A, overall of the n = 3770 participants approached for consent to participate in the data-linkage project 2014-2015, n = 2691 responded (71.4%), with n = 2356 consenting to participate (consent rate of 62.5%). Rates of consent were somewhat higher in existing cohort participants (overall HWR, NZSLA and RP: 63.8%), who were approached for consent twice, compared to the new 2014 refresh participants (57.3%) who were only approached once. However, the lowest rates of response and consent were observed

² current to September, 2014

³ This included 26 participants (21 HWR, 1 NZSLA, 4 RP) who were noted as lost to contact at the time of the first data linkage approach but who had since updated their contact details with the study and thus were approached for the first time in the second approach.

in the first approach to existing participants (Table 3B). Rates of both response and consent markedly higher across both the new refresh and existing cohorts in the second approach protocol (Table 3C), which involved both a mail out with the option to consent/decline as well as a telephone reminder. In the second approach, N = 1618 follow up calls were made with 57.9% of calls resulting in contact with the participant. The implementation of the second approach protocol increased consent rates from 44.3% to 63.5% for the existing cohort.

Table 3A: Number and proportion of response by cohort over all approaches

		Cohort				Total
		HWR	NZSLA	RP	2014 refresh	
Consent	Yes	1403	359	151	443	2356
	No	188	36	9	102	335
	No response	567	245	39	228	1079
Total (N)		2158	640	199	773	3770
Response rate	Overall	73.7%	61.7%	80.4%	70.5%	71.4%
	Consent	65.0%	56.1%	75.9%	57.3%	62.5%
	Decline	8.7%	5.6%	4.5%	13.2%	8.9%

Table 3B: Number and proportion of response by cohort for the first (2014) approach

		Cohort				Total
		HWR	NZSLA	RP	2014 refresh	
Consent	Yes	961	246	108	.	1315
	No	14	0	2	.	16
	No response	1162	393	85	.	1640
Total (N)		2137	639	195	.	2971
Response rates	Overall	45.6%	38.5%	56.4%	.	44.8%
	Consent	45.0%	38.5%	55.4%	.	44.3%
	Decline	0.7%	0.0%	1.0%	.	10.0%

Table 3C: Number and proportion of response by cohort for the second (2015) approach

		Cohort				Total
		HWR	NZSLA	RP	2014 refresh	
Consent	Yes	442	113	43	443	1041
	No	174	36	7	102	319
	No response	248	76	10	228	562
Total (N)		864	225	60	773	1922
Response rates	Overall	71.3%	66.2%	83.3%	70.5%	70.8%
	Consent	51.2%	50.2%	71.7%	57.3%	54.2%
	Decline	20.1%	16.0%	11.7%	13.2%	16.6%

References

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