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Understanding the determinants of consent for linkage of administrative health data with a longitudinal survey

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The Survey of Families, Income and Employment (SoFIE) is a panel income study with a health component, including data linkage to national health databases. This paper investigates factors that predict consent to data linkage. SoFIE participants were asked permission to link their SoFIE records to administrative health data in Wave 3 of data collection. Logistic regression was used to investigate the association of sociodemographic variables with consent to record linkage. Of Wave 3 participants 79.4% consented to health record linkage. Taking into account prior attrition, consent and matching the overall participation rate was 60.9%. Participants reporting Māori, Pacific and Asian ethnicity had lower odds of consenting. There was a strong relationship between the presence of co-morbid disease and consent to linkage. This study has shown that consent to link health information to survey records was high and the survey provides a rich and unique dataset for longitudinal analyses.

Keywords: data linkage; consent; hospitalizations; longitudinal survey

Introduction

The New Zealand longitudinal Survey of Family, Income and Employment (SoFIE) is a rich source of demographic and socioeconomic information, covering eight years from October 2002 to September 2010 (Carter et al. 2010). One of the purposes of SoFIE is to study the relationship between health and social and economic factors. SoFIE includes a question on self-rated health in every Wave and a more detailed health module in Waves 3, 5 and 7. In addition the study links administrative and routinely collected hospitalization and cancer registration data from New Zealand Health Information Service (NZHIS). This is the first time NZHIS data have been linked to a nationally representative longitudinal survey. This will enable linkage to previous hospitalization and cancer registrations and future hospitalizations, cancer registrations and mortality, allowing for analyses of the causal effects of hospitalizations and cancer registration on changes in social and economic circumstances (and vice versa).

Linking data from health datasets to SoFIE survey records required consent from the individual survey participants, which was asked as part of the Wave 3 health module. Most epidemiological studies are unable to obtain consent (to participate and/or to link data) uniformly across participants (Dunn et al. 2004; Harris et al. 2005, Klassen et al. 2005; Kho et al. 2009). Individuals that consent may differ from non-consenters in important respects related to factors under investigation (such as age, sex, ethnicity, and health status).

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Hence measures calculated from studies reflect both factors that determine participation as well as factors that determine disease (Woolf et al. 2000; Young et al. 2001; Dunn et al. 2004; Harris et al. 2005; Klassen et al. 2005) potentially leading to error in point prevalence estimates and/or reported associations between exposures with outcomes.

In many studies the extent of variation in the exposure-outcome association between those actually in the final consented dataset and all those eligible to be in the dataset is unknown. In studies that do have some information on non-consenters, analysis tends to be limited to a description of differences in socio-demographic variables between consenters and non-consenters (Woolf et al. 2000; Young et al. 2001; Dunn et al. 2004; Harris et al. 2005; Klassen et al. 2005).

The aim of this paper is to investigate the relationship between demographic and socio-economic variables and probability of consenting to data linkage and, once consented, ability to match to health records.

Methods

Survey data

The data for the study were obtained from SoFIE, a fixed panel longitudinal survey administered by Statistics New Zealand of approximately 11,500 households (77% response rate) with over 22,000 adults interviewed on an annual basis starting in October 2002.

In SoFIE annual face-to-face interviews are used to collect comprehensive information on demographics, households, income, employment, education, family composition and self-rated health. Every two years (Waves 2, 4, 6 and 8) information on assets and liabilities is collected to monitor net worth and savings. In the alternating years (Waves 3, 5 and 7) information is collected on a number of health dimensions including health-related quality of life, psychological distress and co-morbidities (including asthma, hypertension, heart disease, diabetes, stroke, psychiatric disorders), thus giving rise to the SoFIE-Health study.

Consent

As part of the first SoFIE-Health module (in Wave 3) written consent was requested from participants for the linkage of their SoFIE-Health record with cancer registrations, hospitalizations and (in the future) mortality (Carter et al. 2009). An extract from the consent form is below, the full consent form can be found in (Carter et al. 2009).[1]

> Statistics New Zealand (Statistics New Zealand) sought your consent to link data collected in SoFIE with hospital admissions hospitals, mortality and cancer register information held by the New Zealand Health Information Service (NZHIS). Linking this data will show how factors such as labour market activity, family type and income are related to health events and health outcomes. For example, it will show how hospitalisation impacts on employment and income.
> Wellington Ethics Committee has given ethical approval for this data linking. Even if you have never been admitted to a public hospital in New Zealand, we request your consent to pass your name, address and birth date to the NZHIS. The fact that you have never been in hospital is useful information for the research.

Record linkage

Statistics New Zealand supplied the name, address, sex and date of birth information of consenting SoFIE participants to NZHIS data. Using these variables NZHIS identified each individual's health file number (NHI). Information on all cancer registrations and hospitalizations from 1990 to 2006 was extracted and sent back to Statistics New Zealand for incorporation into the SoFIE dataset. Updates of this information will be requested in the future.

Privacy

The linkage of health information to SoFIE is primarily governed by the *Statistics Act 1975* and *Privacy Act 1993*. In addition ethical approval has been given for this project by the Wellington Ethics Committee.

Analysis

This study utilizes data from Wave 3 of SoFIE (Version 6). Cross-tabulations were used to investigate the probability of consenting to data linkage and the ability to be matched by NZHIS once consented, by demographic and socioeconomic variables. Additionally univariate and multivariable (adjusting for all variables) logistic regression was used to investigate the association of demographic and socio-economic variables with consent to record linkage.

All analyses were conducted using SAS 8.2. All numbers of participants presented in this paper are rounded to the nearest multiple of five, with a minimum value of 10, as per Statistics New Zealand confidentiality protocol so subgroup totals may not sum to overall total number of people. Regression analyses were conducted on unit-level data.

Results

Figure 1 shows the flow of participants from Wave 1 to the Wave 3 interview, the number of people who consented and of those the number who could be matched to an NHI number by NZHIS. There were a total of 22,165 people aged 15 years or older interviewed at Wave 1. Figure 1 and Table 1 show that by Wave 3, 18,230 (82.2%) of the original sample aged 15 years at Wave 1 were re-interviewed. Attrition was greater in younger participants and those reporting ethnicity other than NZ European. Of the 18,230 people who were interviewed at Wave 3, 13,995 (76.8%) consented to having their health records linked to their SoFIE records. Overall 96.4% of participants who consented to linkage were able to be matched to their health file, although this was lower (84.4%) for those of Asian ethnicity. Using Wave 1 participants as the denominator (i.e. taking into account prior attrition, consent and ability to match) the total participation rates ranged from 35.1% to 68.7% (overall 60.9%) across strata of age, sex and ethnicity. Using the Wave 3 participants as the denominator (i.e. only taking into account those who were requested to consent and ability to match), the linked participation rates varied from 54.8% to 79.3% (overall 74.0%). Total participation rates were lowest for younger respondents and those reporting Pacific or Asian ethnicity.

Table 2 describes the distribution of consent to linkage among Wave 3 responders, by demographic and socioeconomic characteristics and health status. There were no significant differences in consent rates by sex or age in univariate and multivariate (adjusting for all variables) analyses. Participants reporting Māori, Pacific and Asian ethnicity had lower odds of consent to linkage than non-Māori, non-Pacific, non-Asian respectively in both

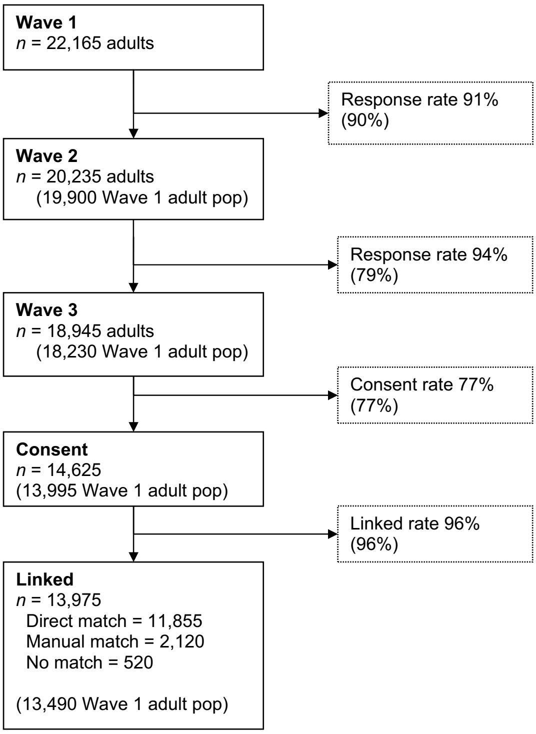

Fig. 1 Flow chart of response, consent and linkage rates.

Table 1 Consent and linkage rates to health data for adult SoFIE participants.

	Wave 1	Wave 3		Consented		Linked		Participation	
	n	*n*	% (Wave 1)	*n*	% (Wave 3)	*n*	% (consent)	% Wave 1	% Wave 3
Age									
15–24	3,800	2,655	69.9	1,990	75.0	1,890	95.0	49.7	71.2
25–34	3,730	2,930	78.6	2,240	76.5	2,125	94.9	57.0	72.5
35–44	4,530	3,900	86.1	2,955	75.8	2,840	96.1	62.7	72.8
45–54	3,755	3,335	88.8	2,535	76.0	2,450	96.6	65.2	73.5
55–64	2,890	2,580	89.3	2,030	78.7	1,985	97.8	68.7	76.9
65 +	3,445	2,840	82.4	2,245	79.0	2,195	97.8	63.7	77.3
Sex									
Female	11,840	9,850	83.2	7,585	77.0	7,355	97.0	62.1	74.7
Male	10,320	8,375	81.2	6,410	76.5	6,135	95.7	59.4	73.3
Total ethnicity*									
NZ European	17,930	14,665	81.8	11,955	81.5	11,630	97.3	64.9	79.3
Māori	2,815	1,930	68.6	1,480	76.7	1,420	95.9	50.4	73.6
Pacific	1,410	830	58.9	540	65.1	495	91.7	35.1	59.6
Asian	1,420	940	66.2	610	64.9	515	84.4	36.3	54.8
Other	430	320	74.4	235	73.4	220	93.6	51.2	68.8
Total	22,165	18,230	82.2	13,995	76.8	13,490	96.4	60.9	74.0

*Total ethnicity—groups are not mutually exclusive as participants can report multiple ethnic groups (sum over ethnic groups >N).

univariate and multivariable analyses. Participants reporting no educational qualifications had lower odds of consenting to linkage (odds ratio 0.7, 95% CI 0.5–0.8) compared to participants holding a degree or higher qualification. However, other measures of socio-economic position were not significant predictors of consent in multivariate analyses. There was a strong relationship between consent to linkage and having any co-morbid disease present (odds ratio 1.7, 95% CI 1.5–2.0 for two or more co-morbid conditions). In contrast self-rated health was not a significant predictor of consenting to linkage.

Discussion

This paper shows that consent to link health information to survey records was high (about 80% of those who were asked) and the process of linkage was highly successful (96%). However, due to attrition between Waves 1 and 3 of SoFIE the percentage of the total study population eventually linked was 61%. Statistically significant factors that predicted consent to data linkage included ethnicity, educational qualifications and presence of co-morbidity. The attrition rate to Wave 3 in SoFIE is comparable to (if not lower than) other international panel surveys (Hauck & Rice 2004; Wilkins et al. 2009).

The level of overall consent by study participants to linkage of their survey data and administrative health data seems to vary considerably, although many of the studies are dissimilar in terms of the research focus, age and sex of participants (Kho et al. 2009). Longitudinal studies that have linked to administrative health data (other than mortality files) have reported varying levels of consent. For example the Australian Longitudinal study on Women's Health obtained consent to link to

Table 2 Odds ratios of consent to data linkage among Wave 3 responders by demographic and socioeconomic variables.

		Consent to NZHIS linkage					
		No		Yes		Univariate	Multivariable*
Wave 1	*n*	*n*	%	*n*	%	OR (95% CI)	OR (95% CI)
	18,230	3,635	19.9	13,995	76.8		
Sex							
Female	9,850	1,960	19.9	7,585	77.0	1	1
Male	8,375	1,675	20.0	6,410	76.5	1.01 (0.93–1.08)	1.01 (0.94–1.09)
Age							
15–24	2,655	525	19.8	1,990	75.0	1	1
25–34	2,930	580	19.8	2,240	76.5	1.03 (0.90–1.17)	0.91 (0.79–1.05)
35–44	3,900	815	20.9	2,955	75.8	0.96 (0.85–1.09)	0.83 (0.73–0.95)
45–54	3,335	705	21.1	2,535	76.0	0.95 (0.83–1.07)	0.79 (0.69–0.91)
55–64	2,580	475	18.4	2,030	78.7	1.13 (0.98–1.30)	0.97 (0.83–1.13)
65–74	2,840	540	19.0	2,245	79.0	1.11 (0.97–1.27)	0.97 (0.82–1.15)
Prioritized ethnicity							
NZ European	14,145	2,530	17.9	11,235	79.4	1	1
Māori	2,030	450	22.2	1,480	72.9	0.75 (0.67–0.84)	0.76 (0.67–0.86)
Pacific	825	280	33.9	490	59.4	0.40 (0.34–0.47)	0.41 (0.34–0.48)
Asian	925	300	32.4	575	62.2	0.43 (0.37–0.50)	0.44 (0.37–0.51)
Other	305	75	24.6	220	72.1	0.65 (0.50–0.85)	0.62 (0.47–0.81)
Standard family type							
Couple only	5,550	1,040	18.7	4,375	78.8	1	1
Couple with children	7,575	1,500	19.8	5,800	76.6	0.92 (0.84–1.01)	1.13 (1.02–1.26)
Sole parent	1,785	385	21.6	1,315	73.7	0.81 (0.71–0.93)	1.00 (0.86–1.16)
Not in a family nucleus	3,315	710	21.4	2,505	75.6	0.84 (0.75–0.93)	0.85 (0.76–0.95)
Labour force status							
Employed	11,590	2,285	19.7	8,935	77.1	1	1
Not employed, looking	415	80	19.3	320	77.1	1.01 (0.79–1.30)	1.20 (0.93–1.56)
Not employed, not looking	6,215	1,270	20.4	4,740	76.3	0.96 (0.89–1.03)	1.03 (0.93–1.14)
Highest education							
Degree or higher	2,415	415	17.2	1,915	79.3	1	1
Post school qualification	6,065	1,150	19.0	4,735	78.1	0.89 (0.79–1.01)	0.82 (0.72–0.93)
School qualification	4,995	1,000	20.0	3,840	76.9	0.83 (0.73–0.94)	0.80 (0.69–0.91)
No qualification	4,760	1,075	22.6	3,505	73.6	0.71 (0.62–0.80)	0.66 (0.58–0.76)
Equivalized household income							
Q1	2,550	585	22.9	1,835	72.0	0.68 (0.60–0.77)	0.82 (0.71–0.95)
Q2	4,265	895	21.0	3,265	76.6	0.78 (0.70–0.87)	0.83 (0.73–0.94)
Q3	3,695	750	20.3	2,805	75.9	0.80 (0.71–0.90)	0.87 (0.77–0.99)
Q4	3,715	720	19.4	2,895	77.9	0.86 (0.77–0.97)	0.90 (0.80–1.01)
Q5	4,010	690	17.2	3,200	79.8	1	1
NZ deprivation							
Q1 (least)	3,545	665	18.8	2,775	78.3	1	1
Q2	3,745	720	19.2	2,925	78.1	0.95 (0.85–1.07)	1.02 (0.90–1.15)

Table 2 (*Continued*)

Consent to NZHIS linkage							
		No		Yes		Univariate	Multivariable*
Wave 1	*n*	*n*	%	*n*	%	OR (95% CI)	OR (95% CI)
Q3	3,170	680	21.5	2,405	75.9	0.83 (0.73–0.93)	0.95 (0.84–1.08)
Q4	4,030	755	18.7	3,125	77.5	0.98 (0.87–1.10)	1.17 (1.03–1.33)
Q5 (most)	3,740	820	21.9	2,760	73.8	0.80 (0.71–0.89)	1.14 (1.00–1.30)
Self-rated health							
Excellent	6,865	1,360	19.8	5,260	76.6	1	1
Very good	6,040	1,155	19.1	4,700	77.8	1.05 (0.96–1.15)	1.02 (0.93–1.12)
Good	3,755	790	21.0	2,855	76.0	0.93 (0.84–1.02)	0.89 (0.80–1.00)
Fair/poor	1,565	330	21.1	1,180	75.4	0.94 (0.82–1.07)	0.85 (0.73–0.99)
Number comorbid disease							
No comorbid	7,835	1,840	23.5	5,995	76.5	1	1
1–2 comorbid	7,935	1,460	18.4	6,475	81.6	1.36 (1.26–1.47)	1.33 (1.23–1.44)
>2 comorbid	1,805	285	15.8	1,520	84.2	1.64 (1.43–1.89)	1.75 (1.51–2.03)

Socio-demographic variables measured at Wave 1; table only contains those with complete data in Wave 1 ($n = 18{,}230$). Prioritized ethnicity allocates one ethnic group to an individual (even if they give multiple responses) and is required for multivariate analysis.
*Adjusted for all variables in table.

administrative records from only 49.3% of participants (Young et al. 2001). This compares to 80% consent in the Asset and Health Dynamics of the Oldest-Old in the USA (Lillard & Farmer 1997) and 92% consent in the UK Millennium cohort (Tate et al. 2006). It is possible that these studies had over-estimated consent rates due to the nature of these studies, particularly around health, and the populations they are researching, the elderly and new mothers, respectively. SoFIE is a nationally representative study with a particular focus on families, income and employment, so the link to health (although it was explained clearly) may not have been as clear as anticipated.

The factors that predict consent to linkage also seem to vary by study. For example in SoFIE neither age nor sex was a statistically significant predictor of consent. Similar findings have been noted elsewhere (Harris et al. 2005; Kho et al. 2009). In contrast, other studies report higher levels of consent amongst older people (Woolf et al. 2000), the middle-aged (Young et al. 2001), younger people (Dunn et al. 2004; Kho et al. 2009), women (Dunn et al. 2004; Kho et al. 2009) and men (Woolf et al. 2000; Kho et al. 2009). In the SoFIE population the only statistically significant socio-economic factor associated with consent was that people with no educational qualifications were less likely to consent.

Ethnicity was an important predictor of consent in SoFIE. Again the findings from the literature are not consistent around the impact of ethnicity on consent (Kho et al. 2009). Other New Zealand studies report lower participation by Māori and Pacific people (Ministry of Health 2003; Statistics New Zealand 2007), although this is not a universal phenomenon, and approaches that utilize culturally appropriate frameworks can minimize participation differences (Gander et al. 2005; Paine et al. 2005). Work in the US suggests that lower participation of ethnic minorities is due to these groups being less frequently asked to participate in studies

(Wendler et al. 2006). This is in contrast with New Zealand, where boosted sampling of Māori and Pacific People in many surveys has led to concern about respondent burden.

The finding that increasing co-morbidities or ill health are associated with increased consent is consistent with some (but not all) studies (Kho et al. 2009). A number of reasons for increased participation have been proposed, including increased individual motivation to participate, gratitude to the health system, and/or contribution to prevention in the future (Klassen et al. 2005). Qualitative research would be useful to investigate these motivations further.

A lower proportion of participants of Asian ethnicity (84.4%) compared to New Zealand European (97.3%) who consented were able to be linked. Potential explanations for this include the possibility that differences in the spelling of names between the SoFIE dataset and health collections meant that deterministic linkage was less successful or that this group may be less likely to have a NHI number. However, the number of people in the New Zealand population without a NHI number is thought to be less than 5% (New Zealand Health Information Service 2009), so the second explanation is less likely.

The linkage of SoFIE survey data to routinely collected health data provides a rich and unique dataset. The retrospective and prospective linkage means that future analyses will be able to look at both social causation and health selection mechanisms of the relationship between health and socioeconomic position, as well as factors predicting future disease and mortality.

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Statistics New Zealand Security Statement

Access to the data used in this study was provided by Statistics New Zealand in a secure environment designed to give effect to the confidentiality provisions of the Statistics Act 1975. The results in this study and any errors contained therein are those of the authors, not Statistics New Zealand.

Note

1. http://www.wnmeds.ac.nz/academic/dph/research/HIRP/SoFIE/SoFIE%20publications.html#Reports.

References

Carter K, Hayward M, Richardson K 2009. SoFIE-Health & NZHIS Data Integration project. SoFIE-Health Report 4. Working Paper. SoFIE-Health Report 4. Wellington: University of Otago.

Carter KN, Cronin M, Blakely T, Hayward M, Richardson K 2010. Cohort Profile: Survey of Families, Income and Employment (SoFIE) and Health Extension (SoFIE-health). International Journal of Epidemiology 39: 653–659.

Dunn KM, Jordan K, Lacey RJ, Shapley M, Jinks C 2004. Patterns of consent in epidemiologic research: evidence from over 25,000 responders. American Journal of Epidemiology 159: 1087–1094.

Gander PH, Marshall NS, Harris R, Reid P 2005. The Epworth Sleepiness Scale: influence of age, ethnicity, and socioeconomic deprivation. Epworth Sleepiness scores of adults in New Zealand. Sleep 28: 249–253.

Harris T, Cook DG, Victor C, Beighton C, Dewilde S, Carey I 2005. Linking questionnaires to primary care records: factors affecting consent in older people. Journal of Epidemiology and Community Health 59: 336–338.

Hauck K, Rice N 2004. A longitudinal analysis of mental health mobility in Britain. Health Economics 13: 981–1001.

Kho ME, Duffett M, Willison DJ, Cook DJ, Brouwers MC 2009. Written informed consent and selection bias in observational studies using medical records: systematic review. British Medical Journal 338: b866.

Klassen AF, Lee SK, Barer M, Raina P 2005. Linking survey data with administrative health information. Canadian Journal of Public Health 96: 151–154.

Lillard LA, Farmer MM 1997. Linking Medicare and national survey data. Annals of Internal Medicine 127: 691–695.

Ministry of Health 2003. NZ Food NZ Children: Key results of the 2002 Children's Nutrition Survey. Wellington: Ministry of Health.

New Zealand Health Information Service 2009. National Health Index: NHI frequently asked questions. http://www.nzhis.govt.nz/moh.nsf/pagesns/266?open (accessed 16 March 2009).

Paine S-J, Gander PH, Harris RB, Reid P 2005. Prevalence and consequences of insomnia in New Zealand: disparities between Maori and non-Maori. Australian & New Zealand Journal of Public Health 29: 22–28.

Statistics New Zealand 2007. A Report on the 2006 Post-enumeration Survey. Wellington: Statistics New Zealand.

Tate AR, Calderwood L, Dezateux C, Joshi H, The Millennium Cohort Study Child Health G 2006. Mother's consent to linkage of survey data with her child's birth records in a multi-ethnic national cohort study. International Journal of Epidemiology 35: 294–298.

Wendler D, Kington R, Madans J, Wye GV, Christ-Schmidt H, Pratt LA, Brawley OW, Gross CP, Emanuel E 2006. Are racial and ethnic minorities less willing to participate in health research? PLoS Medicine 3: 201–210.

Wilkins R, Warren D, Hahn M 2009. Families, incomes and jobs, volume 4: A statistical report on Waves 1 to 6 of the HILDA survey. Melbourne: Melbourne Institute of Applied Economic and Social Research, The University of Melbourne.

Woolf SH, Rothemich SF, Johnson RE, Marsland DW 2000. Selection bias from requiring patients to give consent to examine data for health services research. Archives of Family Medicine 9: 1111–1118.

Young AF, Dobson AJ, Byles JE 2001. Health services research using linked records: who consents and what is the gain? [see comment]. Australian & New Zealand Journal of Public Health 25: 417–420.