Consent to link health data: older adults in New Zealand

A thesis presented in partial fulfilment of the requirements
for the degree of

Master of Arts

In

Psychology

At Massey University, Manawatū,

New Zealand.

Laura Jessie Crawford

2017
Abstract

With administrative data increasingly being recorded electronically, data linkage has become a popular method of research. It involves the linkage of two data sets – survey and administrative data, in the current study – to create a wider and more varied data set, with which a greater number of research questions can be examined. Seeking consent from participants to link their data is an ethical and legal requirement. However, consent seeking may create systematic bias as likelihood of consenting may be associated with a variety of health and socioeconomic variables. Variables associated with consent were examined for linkage between the Health, Work Retirement longitudinal study and Ministry of Health data sets in New Zealand. Unlike previous studies of this type, participants were older adults. Binary logistic regression revealed that Māori ethnicity (OR 0.68), Diabetes (OR 0.66), and participating for more survey waves (OR 1.88) were significantly associated with consent. The model explained 7 to 10% of the variance in consent, suggesting that older adults are not greatly influenced by these variables. Implications for research and policy are discussed.
Acknowledgements

I would like to thank my supervisors Fiona Alpass and Andy Towers for your endless patience and excellent feedback, as well as keeping me on the right track when I was unsure of my direction. Andy especially, thank you for sending me down this fascinating and important avenue of study. To the broader Health and Ageing Research Team, thank you for letting me participate in your great work.

Miki Seifert, the most observant and generally excellent grammar enthusiast I know, thank you for editing the final draft. This thesis is better for your input.

Maddy, Shelly, Luke, Adam, Damien, and Mike thank you for supporting and encouraging me at various times throughout my thesis, especially when it got difficult. Finally, to the rest of my friends, family, and colleagues who supported me in any way: thank you. You made this journey wonderful.
Consent to link health data: older adults in New Zealand

Contents

Abstract .................................................................................................................................................. 2
Consent to link health data: older adults in New Zealand ................................................................ 6
  A quick introduction to data linkage .................................................................................................. 6
Literature Review: Consent to Data Linkage in Health and Ageing Research ...................................... 8
  Increasing focus on data linkage in health research ......................................................................... 9
Health and ageing research using data linkage .................................................................................. 12
  Linked data can reveal reasons for health service use ..................................................................... 13
  Mortality data linkage enables study of associations ...................................................................... 13
  Linked data can show the impact of chronic conditions .................................................................. 14
Consent bias can impact research quality ......................................................................................... 16
Consent bias is a sub-set of response bias ......................................................................................... 18
Consent bias likely impacts health research quality ......................................................................... 18
Literature review: Consent related variables ..................................................................................... 20
  Consent rates tend to be high, but differ across studies ................................................................. 20
  Gender and age aren’t clearly associated with consent .................................................................... 21
  Minority ethnicity can reduce consent rates .................................................................................. 22
  Socioeconomic factors have an unclear association with consent .................................................. 23
Health is often significantly related to consent ................................................................................ 24
More and longer participation increases consent rates ..................................................................... 26
Consent bias for older adults hasn’t been researched ..................................................................... 27
Research Aims ................................................................................................................................... 27
Method ................................................................................................................................................. 30
Participants ......................................................................................................................................... 30
Measures ............................................................................................................................................. 32
  Consent ........................................................................................................................................... 32
  Demographics .................................................................................................................................... 32
  Socioeconomic status ...................................................................................................................... 33
  Health status .................................................................................................................................... 33
Analysis ............................................................................................................................................... 34
Bivariate analysis ............................................................................................................................... 34
Multivariate analysis .......................................................................................................................... 34
Results ........................................................................................................................................ 36

Health conditions and likelihood of consent ........................................................................ 38

Binary logistic regression ........................................................................................................ 39

Assumption testing .................................................................................................................. 40

Results of the model ................................................................................................................ 41

Discussion ............................................................................................................................... 44

This study examined consent bias for older adults .............................................................. 44

Māori ethnicity was negatively related to consent ............................................................... 44

Overall health was not associated with consent ..................................................................... 46

The Short Form Health Survey may not be associated with consent ................................... 46

The health-consent relationship may be different for older adults ..................................... 47

Diabetes was negatively associated with consent ................................................................. 47

Participating in more survey waves increased consent ......................................................... 49

The regression model was a poor predictor of consent ......................................................... 49

A note of caution about study limitations ............................................................................. 50

The future of consent in data linkage research ...................................................................... 51

Implications for health policy and practice .......................................................................... 52

References ............................................................................................................................... 54