

doi: 10.1111/1753-6405.12797

## The acceptability of participating in data linkage research: research with older Australians

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Currently, 15% of Australians are older than 65 years of age and, by 2031, almost 20% will be aged over 65.<sup>1</sup> In Australia, \$14.8 billion is spent annually on aged care services.<sup>2</sup> Since the population is ageing, gaining a greater understanding of the service utilisation and health outcomes of the older population is essential in developing interventions and improving healthcare. To achieve this, we could better use administrative data that is already routinely collected. Data integration involves linking datasets that are held by different data custodians into a combined resource, i.e. a registry, which can create research opportunities and eventually improve health and related outcomes for the population. Data linkage capacity in Australia has greatly improved in recent years due to investment by federal and state government agencies.<sup>3</sup> Successful data registries in the healthcare sector have shown true positive net value, meaning low investment with substantial benefits in improving the health of the cohorts they monitor.<sup>4</sup> In South Australia, a registry to monitor its older population is currently being planned. This registry will integrate existing datasets in health and aged care, which will efficiently allow for the evaluation and identification of quality aged care services, products and practices.

Australians are increasingly concerned about the privacy of their data, but the biggest concerns relate to online services and identification fraud.<sup>5</sup> Australians may

be supportive of research that uses linked data; however, there have been conflicting findings as to whether formal consent from individuals should be sought, and the views of the older population have not been elicited specifically.<sup>6,7</sup> A previous survey suggested half of Australians would expect consent to be sought for the use of de-identified health information for research purposes, but the respondents were not specifically asked if they would expect an opt-in or opt-out approach to consent.<sup>8</sup> The objectives of the current study were to determine if older Australians would find it acceptable to be part of the proposed registry and to explore different methods of consent.

An online survey of 2000 older people (aged 55 years and over) living in Australia was conducted to examine the above objectives. Although this limits the sample to those who had internet access, previous research has shown 71% of older Australians report recently using the internet (2015 figure).<sup>9</sup> The survey questions were designed by researchers involved in the study and conducted by an external company that has a database of people who have signed up to complete surveys (PureProfile). The survey was sent to people in this database based on their eligibility (Australia only and aged 55 years and over) and was designed to be representative of the older population of Australia nationally. The respondents were paid a small participation fee for being involved. The study was approved by the Southern Adelaide Clinical Human Research Ethics Committee.

The characteristics of the participants are shown in Table 1. Of the study participants, 66.7% (n=1,333) found it acceptable to have data that was collected in an aged care assessment de-identified, accessed and used for health research purposes; 11.9% (n=238) answered 'not sure'; and 21.5% (n=429) said that they would not find this acceptable. (Where a person had not recently completed an aged care assessment, a hypothetical version of this question was asked.) Of those who said 'yes' to having their de-identified data used for health research, 33.9% (n=452) said 'yes' without any need for consent; 40.5% (n=540) said they would only find it acceptable if they were asked first (opt-in approach); and 25.6% (n=341)

**Table 1. Characteristics of study participants (N=2000).**

Characteristic	%	National population profile <sup>a</sup>
<b>Sex</b>		
Female	50.6	50.6
<b>Age<sup>b</sup></b>		
55–64 years	50.6	45.7
65–74 years	34.0	29.1
75+ years	15.4	25.2
<b>Location</b>		
NSW	32.5	32.2
VIC	25.1	24.9
QLD	20.4	20.1
SA	7.4	7.4
WA	10.4	10.4
ACT	1.7	1.7
TAS	2.3	2.3
NT	0.4	1.0

Notes:

a: National statistics from Australian Bureau of Statistics (2011 Census data).<sup>10</sup>

b: National percentages for age categories are for the population aged 55 years and older. Survey designed to over include population aged 65 years and older.

said they would agree if they were given the opportunity to opt-out of the study. Of those who said 'yes' or 'not sure' to having their data accessed (n=1,571), 84.1% participants (n=1,321) found it acceptable to have their wider health data linked for the registry (66.1% of the total study population). Of the total participants, 11.1% (n=221) had recently completed an aged care assessment and, of these, 80.1% (n=177) said that they would find it acceptable to have that data de-identified, accessed and used for health research purposes; 10.4% (n=23) answered 'not sure'; and 9.5% (n=21) answered that they would not find it acceptable.

This study had strengths and limitations. The study included a large sample of the older population of Australia, including both those currently receiving aged care services and those likely to access the services in the future. This type of study had not yet been conducted in an Australian setting and it is one of the few conducted on this topic internationally. Data privacy issues are of increasing interest and this study would be useful to apply to a wide variety of settings. The study was a nationally representative sample in terms of gender and location, but we were unable to meet the national proportions for people aged over 75

The authors have stated the following conflict of interest: SLH, RM, MI and MC are researchers for the Registry of Older South Australians, which is funded by the Premier's Research Industry Fund.

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years (15.4% in this study compared to 25.2% nationally); therefore, we had more participants of younger age groups. Furthermore, only those who were registered with the company who conducted the survey were asked to participate, therefore, this may have introduced a selection bias.

In conclusion, the majority (66%) of the older population in Australia would find it acceptable to have their data used for the purposes of a registry (accessed and linked). However, there were differences between which method of consent would be most favourable. A higher proportion (80%) of respondents who had already completed an aged care assessment found the inclusion of their data in a registry acceptable.

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