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Considerations of response bias and value in linking an existing longitudinal cohort study with national health record data

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Objective

Longitudinal cohort studies remain important sources of information in health and epidemiological research and represent a significant investment of resources. The maintenance of these cohorts over time and the representativeness of retained participants are important considerations for researchers. For those weighting the benefits of augmenting a longitudinal cohort study with data linkage to national health records, the potential for bias in consent and match rates and the utility of the newly obtained data are also key considerations. This study presents an analysis of bias associated with consent to participate and record matching in an established longitudinal cohort of older persons. We present the unique outcomes generated from this national health record data linkage project and the opportunities such variables present for longitudinal cohort studies.

Approach

The New Zealand Health, Work and Retirement study is a biennial survey of persons aged 55–85 which commenced in 2006. Over the past decade, additional cohorts have been recruited to the study, with $n = 9003$ older New Zealand residents participating to the year 2015. In 2013 the study began an approach to active survey participants for consent to link their longitudinal survey data to national health record data held by the New Zealand Health Information Service, including data related to hospital events, the New Zealand Cancer Registry, pharmaceutical data and mental health data. We compare self-reported longitudinal health trends associated with consent/declination to participate as well as for record match success and failure. Key outcomes derived from these national datasets for the purposes of the Health, Work and Retirement Study are described.

Results

Consent (62.5%) and declination (8.9%) to participate in the data linkage project are described in terms of the corresponding longitudinal self-reported health and socio-demographic trends for these groups. Successful and unsuccessful matches of participants to national health record data are also described. The calculation of outcomes from each of the linked datasets obtained and their potential utility in building upon existing longitudinal cohort data are also presented.

Conclusion

National health record data linkage presents a potentially valuable source of data to supplement and replicate findings related to health outcomes and expenditure derived from longitudinal cohort surveys. The challenges and successes of the New Zealand Health, Work and Retirement survey data linkage project touch upon considerations pertinent to evaluating the value of augmenting existing and ongoing longitudinal survey cohort for other researchers.

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