

Epidemiology / Prevalence, incidence, and outcomes of MCI and dementia

Big data and dementia in New Zealand

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Abstract

Background: Research is increasingly looking at how routinely collected health and social care data can be used to influence policy and service design, however the accuracy of such data in New Zealand is not known. Estimates suggest there are 62,000 people living with dementia in NZ, projected to reach 170,000 by 2050, however these figures are extrapolated from overseas prevalence data and do not take into account a variety of factors including NZ's unique demography, specifically Māori and Pacific Islanders who are at higher risk of dementia. Ideally, we would conduct a NZ based dementia prevalence study to obtain accurate data in all the major NZ ethnic groups, however the time and cost required to do this could be prohibitive. The use of routinely collected data may provide a cost-effective alternative or parallel process to assess and monitor dementia in NZ, as well as examine other characteristics which potentially modify the risk of dementia and adverse outcomes. It is unclear whether routinely collected data is a good proxy-measure, given approximately a third of people with dementia never receive a specialist diagnosis, dementia coding is poor even for those who are diagnosed, and there are inequities in how non-European's access services.

Method: A small-scale dementia prevalence study is currently being completed in two geographic areas of South Auckland. Interviews are being completed by bi-cultural bilingual interviewers in a number of different ethnic groups including Asian, Maori, NZ European, and Pacific Islanders. Routinely collected health and social care data for the same geographic areas are also being collected.

Result: Data collection is due to be completed in the first half of 2019, following which the sensitivity and positive predictive value of the routinely collected dataset will be assessed.

Conclusion: Routinely collected data can be a rich source of information, particularly in populations which are little researched or where further information is needed. In NZ little is known about the extent of dementia, and whether this differs across the major ethnic groups. It is hoped that this research will provide a starting point for robust collection of dementia healthcare information in NZ.