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Dementia case ascertainment using aged care assessment data

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Clinical Quality Registries (CQRs) can improve the quality and safety of care by benchmarking clinical practice, informing policy and service design, feeding information back to providers, and complementing research about the effectiveness of care.¹ Given their effectiveness for driving improvements in practice,² ongoing CQRs have been established in many clinical domains internationally. National CQRs for dementia, however, are relatively new and currently limited to a cluster of Scandinavian countries.³ New dementia CQRs are being developed and implemented in several countries. For example, the Australian Dementia Registry (ADNet) ultimately aims to capture and monitor all persons with dementia or mild cognitive impairment at the point of diagnosis via memory or private specialist clinics.⁴ However, registries must cover a significant proportion of the population they intend to monitor. Limitations in coverage can stifle their benefits³ and efforts to maximise coverage are therefore important. Notably, dementia diagnosis often occurs outside of memory or private specialist clinics,⁵ so these settings have limited capacity to capture the entire eligible population of individuals with dementia.

To overcome this, we assessed the feasibility of using administrative data from aged care assessments as an entry point into the Australian dementia CQR. Assessments for

aged care eligibility and funding allocation are compulsory and national in Australia. Since up to two-thirds of older people will access an aged care service in their lifetime⁶ and 21–47% of these people have dementia,⁷ assessments can be a valuable resource for both epidemiological monitoring and CQR capture. Two prior cohort studies have assessed the value of aged care assessments for estimating dementia prevalence and incidence, but the proportion of the whole population of people with dementia that can be captured using these data has not yet been examined.^{8,9} As such, this study aimed to establish the extent to which aged care assessment data can capture the total national population of people with dementia.

We conducted a cross-sectional examination of aged care assessment data for all Australian older people (aged 65 years and over) who have accessed government-subsidised home care packages, respite or transition care, or residential aged care services from 2009 to 2015. This data is available in the Registry of Senior Australians (ROSA)¹⁰ and is descriptively compared here with national prevalence and incidence estimates by the Australian Institute of Health and Welfare (AIHW).¹¹ According to these estimates, there were 341,323 people aged 65 years or over living with dementia in Australia (prevalent cases) in 2016, with 80,986 new cases (incident cases) in that year.¹¹ These estimates were derived by applying pooled prevalence rates from Australasian, Western European, and North American prevalence studies to the Australian estimated resident population figures for 2016.¹² For this analysis, we used dementia diagnoses recorded by clinicians when assessing aged care service eligibility and at entry into permanent aged care. Both assessments require evidence of the diagnosis by a health care professional. ROSA was approved by the University of South Australia and Australian Institute of Health and Welfare ethics committees.

Between 2009 and 2015, an average of 37,661 new cases of dementia was identified each year using aged care assessments (Table 1), which represent 46.5% of the national estimated 80,986 new (incident) cases aged over 65 years in the Australian population. At the end of 2015, there were 135,555 people aged over 65 years alive with dementia

identified via aged care assessments, which was 39.7% of the 341,323 people aged over 65 years estimated to be living with dementia in the general population in 2016. Of these prevalent cases, 89,648 (66.1%) were women, 13,406 (9.9%) were aged 65 to 74 years, 45,467 (33.5%) were aged 75 to 84, 66,048 (48.7%) were aged 85 to 94, and 10,634 (7.8%) were over 95 years.

Nearly 40% of estimated prevalent cases of dementia can be captured using national aged care assessment data, with more than 37,000 people with dementia newly identified in aged care assessment data each year. This high capture rate demonstrates the utility of home and residential aged care assessments as an alternative point of entry for a registry and to inform national prevalence and incidence estimates. Although some of these cases will be identified for a dementia registry earlier, at diagnosis in specialist clinics, others will not. Our results are consistent with an earlier study in which aged care assessment data had the highest capture rate (79.3%) of any included data source (compared to self-report, cause of death data, pharmaceutical data, or hospital data).⁸ Combining aged care assessment data with other existing data sources, which can include hospitalisation records, other community care service data (e.g. from the Commonwealth Home Support Program), general practitioner data, medication dispensing records, and existing cohort studies, can maximise coverage. Using multiple data sources is important given that each source will produce a unique population, based on differences between those who interact with each service.⁹

There are important limitations to using aged care assessment data to capture the full population of people with dementia. This includes under- and biased ascertainment, because only those who access aged care and those with a formal diagnosis of dementia are included. It is estimated that only half of people with dementia receive a formal diagnosis⁵ and those who do tend to have higher levels of education, be married and live in metropolitan areas.¹³ People who access aged care services tend to be older, with more functional and cognitive impairment and less social support than people who do not use aged care.¹⁴ Other limitations include that the veracity of

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the diagnosis recorded in the aged care assessment cannot be confirmed, although a recent international review demonstrated that diagnosis could be confirmed in 70–90% of dementia cases identified in administrative datasets.¹⁵ We were also unable to include the approximately 28% of people who were approved for, but did not subsequently access, aged care services.¹⁶ In addition, these assessments often occur later in the disease path and this limits the potential benefits of monitoring early clinical care. Nonetheless, a large proportion of individuals with dementia use aged care services (with increasing entrants every year) and many of these will not be identified elsewhere. These people should benefit from the monitoring and evaluation that a dedicated clinical quality registry can offer. As such, aged care assessments should be considered as valuable points of entry for dementia CQRs internationally.

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Table 1: People aged 65 years or older with dementia in ROSA cohort, by calendar year.

Year	Identified during year				At 31 December of year			
	Identified using ACAP	Identified using ACFI	Total unique identified	Deceased ^a	Total alive with dementia	Total alive in PRAC with dementia	Total alive in HCP with dementia	Total alive not currently in HCP or PRAC ^b
Pre-2009	-	-	-	-	114,605	78,052	8,740	27,813
2009	25,629	25,075	41,740	32,039	124,763	87,057	9,373	28,333
2010	24,273	20,383	35,998	33,565	127,621	89,640	9,488	28,493
2011	24,377	21,243	36,841	35,056	129,882	91,339	10,206	28,337
2012	24,625	21,237	37,128	36,026	131,509	91,926	10,539	29,044
2013	23,654	21,433	36,832	35,362	133,471	93,013	10,606	29,852
2014	23,335	21,799	37,416	36,785	134,580	93,523	9,965	31,092
2015	22,048	22,768	37,673	37,199	135,555	94,649	10,065	30,841

Notes:

ACAP = Aged Care Assessment Program; ACFI = Aged Care Funding Instrument; HCP = Home care package; PRAC = Permanent residential aged care

a: Includes those identified and deceased within same year as well as those identified in previous years

b: Includes those in respite or transition care, or not currently using a service