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TITLE

Cohort profile: Dementia in the Registry of Senior Australians

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ABSTRACT

Purpose

Clinical quality registries (CQR) are being established in many countries to monitor, benchmark, and report on the quality of dementia care over time. Case ascertainment can be challenging given that diagnosis occurs in a variety of settings. The Registry of Senior Australians (ROSA) includes a large cohort of people with dementia from all Australian states and territories identified using routinely-collected aged care assessment data. In ROSA, assessment data is linked to information about aged and health service use, medicine dispensing, hospitalisations, and the National Death Index. The ROSA dementia cohort was established to capture people for the Australian dementia CQR currently in development who may not be identified elsewhere.

Participants

There were 313,544 people with dementia identified in aged care assessments from 2008 to 2016. Individuals were 83.6 years old on average at cohort entry (e.g. when first identified with dementia on an aged care assessment), and 60.6% were female. More than 36% were first identified at entry to permanent residential aged care. The cohort recorded more severe cognitive impairment than other international dementia registries.

Findings to date

The cohort has so far been used to demonstrate a declining prevalence of dementia in individuals entering the aged care sector, examine trends in psychotropic medicine prescribing, and to examine the impact of dementia on aged care service use and outcomes.

Future plans

The ROSA dementia cohort will be updated periodically and is a powerful resource both on its own and as a contributor to the Australian dementia CQR. Integration of the ROSA dementia cohort with the dementia CQR will ensure that people with dementia using aged care services can benefit from the ongoing monitoring and benchmarking of care that a registry can provide.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The ROSA dementia cohort includes large cohort of people with dementia from all Australian states and territories, with a wide breadth of linked data to allow for monitoring of care.
- The ROSA dementia cohort does not include people who do not have a diagnosis of dementia or those who have not used government-subsidised aged care services.
- Entry to the ROSA dementia cohort occurs at identification on aged care eligibility assessments, which can be sometime after dementia symptom onset or formal diagnosis. This limits the potential for monitoring early clinical care.

INTRODUCTION

Registries are powerful tools for research and monitoring of clinical care because they facilitate population-level surveillance over time [1,2]. As the global prevalence of dementia rises [3], dementia-related registries are being established internationally to complement clinical research and improve the quality of care for people with this condition [4]. Methods of capturing cases of dementia vary between registries but usually include reporting from specialist clinics and hospitals. Importantly for a dementia registry, diagnosis occurs in a variety of settings and therefore capturing the whole population can be challenging [4].

Dementia is a common chronic health condition in Australia, affecting an estimated one in 10 people aged over 65 years [5]. More than 400,000 people are estimated to be living with dementia in Australia, 25,000 of whom are aged under 65 years [5]. The Australian Dementia Network (ADNeT) Clinical Quality Registry (CQR) is a new national dementia CQR established to monitor, benchmark, and report on the quality of care for people with mild cognitive impairment (MCI) and dementia over time [6]. The ADNeT Registry enrols participants at the point of diagnosis in memory or private specialist clinics and will track longitudinal outcomes via patient and carer reported outcome measures as well as linkage with administrative datasets.

However, many people with dementia or MCI may be diagnosed in other settings [7]. Given the high prevalence of dementia among those accessing government-subsidised aged care services [8], existing aged care assessment data has great potential to contribute to the capture of individuals into the ADNeT CQR. Approximately 47% of Australian residential care users and 21% of home care users have a recorded diagnosis of dementia [8]. It is estimated that aged care assessments conducted from 2009 to 2015 captured approximately 36% of the estimated total population of people with dementia in Australia (prevalent cases) at the end of 2015 (unpublished data). Therefore, understanding and studying the cohort of individuals with dementia captured within the aged care sector can significantly contribute to our understanding of the individuals that may not be captured earlier for a national CQR. Information about health service use, medicines, hospitalisations, mortality and other information can then be monitored for these individuals over time.

In our current evaluation we have examined (a) the demographic and clinical features of people with dementia using Australian aged care services and the extent to which these are representative of the broader population of people with dementia in Australia, and (b) the comparability of data captured in aged care datasets to selected established international dementia registries. This will allow for better understanding of the characteristics and

limitations of this cohort for monitoring the quality of care and outcomes for people living with dementia in Australia.

COHORT DESCRIPTION

Design and data sources

A national cohort of all non-Indigenous Australians aged 65 and over who have accessed government-subsidised aged care services from 1997 to 2017 (and updated regularly) is captured in the Registry of Senior Australians (ROSA). In ROSA, national aged care assessment data are linked with information about aged care service use, health service use, medication dispensing, hospitalisations, and death records [9] of individuals that entered the aged care sector. Specifically, assessments within the aged care sector are conducted to determine eligibility for government-subsidised services (by Aged Care Assessment Teams, established in 2003; ACAT) or to identify funding requirements in residential aged care (Aged Care Funding Instrument, established in 2008; ACFI). In both assessments assessors are clinically-trained medical, nursing or allied health professionals who identify the level of care need based on functional and cognitive limitations [10,11]. Data from assessments, as well as aged care service use, are provided to ROSA from the Australian Institute of Health and Welfare National Aged Care Data Clearinghouse.

These data are subsequently linked with information about government-subsidised health service use from the Medicare Benefits Schedule (MBS), medicine dispensing from the Pharmaceutical Benefits Scheme (PBS), state based hospital records (for South Australia, New South Wales, and Victoria) and mortality data from the National Death Index (NDI). The ROSA established this cross-sector data linkage for research purposes and aims to assess the effectiveness, appropriateness, and quality of aged care services provided to older individuals over time. In its entirety, the historical ROSA cohort includes over 2.8 million individuals, including 1.2 million who have had aged care eligibility assessments for substantial aged care services like permanent residential care, home care packages, residential respite care and transition care.

Ethical approval for ROSA was provided by the University of South Australia (reference ID200489), Australian Institute of Health and Welfare (reference EO2018/1/418), South Australian Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South Wales Population and Health Services (reference 2019/ETH12028) Human Research Ethics Committees.

Here we present results of a cross-sectional evaluation of the people with dementia identified in aged care assessment data (hereafter referred to as the 'ROSA dementia cohort') between July 1 2008 and May 31 2016. The entry point to the ROSA dementia cohort is the first aged

care assessment where a recording of dementia was made, though the person may have entered the ROSA with an earlier assessment (on which a dementia diagnosis was not recorded). Entry is distinct from the date of diagnosis, which will have occurred earlier. Where a person is identified from medication prescribing records, data from the closest aged care assessment is included here for cohort profiling.

Dementia ascertainment

Dementia is determined from aged care eligibility assessments (conducted by Aged Care Assessment Teams; ACAT), assessments for funding in permanent residential care (conducted using the Aged Care Funding Instrument; ACFI), and from pharmaceutical data as captured in the Pharmaceutical Benefits Scheme (PBS) In assessments, assessors record up to 10 (ACAT) or up to three (ACFI) major diseases or disorders that have an impact on the person's need for assistance with activities of daily living and social participation, together with documented evidence of a diagnosis from a medical practitioner. Assessors can record one or more types of dementia or have the option to classify the dementia as 'unspecified' based on the medical record. In addition, medicines prescribed for the treatment of Alzheimer's disease are not dispensed for any other reason. Any person with who has been dispensed donepezil (Anatomical Therapeutic Chemical Classification System code, ATC N06DA02),

galantamine (ATC code N06DA04), rivastigmine (ATC code N06DA03) or memantine (ATC code N06DX01) can be classified as having dementia.

Minimum data set

The data available for the ROSA dementia cohort is presented in Table 1, with comparable data from other established dementia registries. Registries included for comparison were chosen based on their broad coverage and the availability of data for comparison here. They include one clinical quality registry (the Swedish Dementia Registry (SveDem)), two epidemiological dementia registries (French National Alzheimer Database (BNA); Registry of Dementia of Girona, Spain (ReDeGi)) and one dementia research registry (United States National Alzheimer's Coordinating Centre Unified Dataset (NACC-UDS)).

151 Table 1. Comparison of the ROSA Dementia Cohort and International Dementia Registries, Minimum Dataset Available

	ROSA Dementia Cohort	Swedish Dementia Registry [12]	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [13]	Registry of Dementia for Girona [14]	National Alzheimer's Coordinating Centre Unified Data Set [15]
Country	Australia	Sweden	France	Spain [a]	USA
Demographics	Date of birth Sex Living arrangements Country of birth Language Region Marital status Socioeconomic status [b] Carer availability Carer relationship Carer co-residency (y/n)	Age Sex Living arrangements Driver's licence (y/n) Weapons licence (y/n)	Date of birth Sex Living arrangements Area of birth Education	Date of birth Sex Living arrangement Nationality Region Occupation Education Marital status	Date of birth Sex Living arrangements Ethnicity Language Education Marital status Handedness Carer demographics
Clinical characteristics	Type of dementia	Type of dementia Family history of dementia BMI Total number of diagnostic tests	Type of dementia Procedure type [c]	Type of dementia Family history of dementia Aged at symptom onset (estimated) Date of diagnosis	Type of dementia Family history of dementia Age at dementia symptom onset Smoking status/volume Alcohol use

		Time needed for diagnosis Recommended diagnostic workup (y/n)			BMI Blood pressure Resting heart rate Vision, hearing Imaging (yes/no)
Cognitive testing	PAS-CIS score [d]	MMSE score	MMSE score	MMSE score BDRS score CDRS score	MMSE score [e] MOCA score [f] Neuropsychological battery [g] CDRS score NPI score
Care use	All government funded aged care (inc. dates and priority) including: • Respite care • Home care • PRAC • Transition care • Other home and community support services Health service use [h]	Respite care (y/n) Home care (y/n) PRAC (date of moving, type of home) [a]	Date of entry to residential care Psychosocial intervention (yes/no)	NA	NA
Medications	All (including dosage and dates) [i]	Anti-dementia (y/n) Antidepressants (y/n) Antipsychotics (y/n)	Anti-dementia (y/n) Antidepressants (y/n) Antipsychotics (y/n)	Anti-dementia (y/n) Antidepressants (y/n) Antipsychotics (y/n)	All (self-reported; y/n)

		Anxiolytics (y/n) Hypnotics (y/n) Cardiovascular drugs (y/n) Total number of drugs	Anxiolytics (y/n) Hypnotics (y/n) Serious drug-related adverse event (y/n)		
Health and wellbeing	Comorbidities [j] Cornell Scale for Depression in Dementia [d]	QUALID [d] Falls, ulcers, malnutrition, oral health (screening and intervention) [d] Links to other registries		Present hypertension, diabetes mellitus, dislipidemia, stroke, thyroid disease History of depression	Comorbidities (self-reported) Hachinski Ischemic Score Parkinson's Disease Rating Scale Geriatric Depression Scale Neurological exam
Function	Activity limitations	IADL score [a]	IADL score		Functional Assessment Questionnaire
Death	Date of death Causes of death	Time to death (months)	Date of death	NA	Date of death

BDRS=Blessed Dementia Rating Scale ; BMI=Body mass index; CDRS=Clinical Dementia Rating Scale; IADL=Instrumental Activities of Daily Living [16]; MMSE=Mini-mental Status Examination [17]; NA=Not available; NPI=Neuropsychiatric Inventory; PAS-CIS=Psychogeriatric Assessment Scale-Cognitive Impairment Scale; PRAC=Permanent residential aged care; QUALID=Quality of Life in Late-Stage Dementia scale [18]; SD=Standard deviation; USA=United States of America.

[a] Regional only - Girona

[b] Measured using the Index of Relative Socio-economic Disadvantage compiled by the Australian Bureau of Statistics

[c] Consultation, neuropsychological assessment, day-hospital visit, or group session

[d] PRAC only

[e] Version 1,2 (until March 2015)

[f] Version 3 (from March 2015)

[g] Includes Logical Memory IA (Immediate) and IIA (Delayed), Digit Span Forward, Digit Span Backward, Category Fluency, Trail Making Test, Digit Symbol, Boston Naming Test

[h] Government-subsidised health care services only (i.e. not privately funded), including hospitalisation, emergency department, and ambulance service records for some states.

[i] Government-subsidised medicines only

[j] 204 possible comorbidities recorded by assessors or 46 captured from a medication-based co-morbidity measure

ROSA includes comprehensive demographic data and information about aged and health care service use, including service entry and exit dates. All prescription-based medicine dispensing is recorded by the PBS, facilitating monitoring of medicine dosage, duration, and polypharmacy. Information about family history of dementia, diagnostic procedures, or other clinical details (aside from comorbidities) is not available. ROSA also does not include privately-funded health service use.

Assessments conducted for financial purposes at entry into residential aged care are repeated when care needs change. These include a standardised neuropsychological assessment. While most dementia registries include the Mini-Mental Status Examination (MMSE), copyright restrictions have precluded its widespread clinical use in Australia. Instead, the Psychogeriatric Assessment Scale-Cognitive Impairment Scale (PAS-CIS) [19] is conducted where cognitive impairment is suspected or known. The PAS-CIS correlates strongly with the MMSE [20]. A Cornell Scale for Depression (CSD) [21] is conducted where symptoms of depression and dysthymia are present. Functional dependence is rated across domains (including nutrition, mobility, personal hygiene, toileting, continence, home maintenance, and transport) though a validated measure like those used in other registries is not included.

Cohort characteristics

There were 313,544 people in the ROSA dementia cohort over the capture period (Table 2). Detailed demographic data on the cohort appears in Supplementary Table 1. The cohort is representative of the geographical spread of the Australian population with the majority living in New South Wales, Victoria, and Queensland (76.3%, compared to 77.4% of the general population). Similarly, 33.9% of the ROSA dementia cohort live outside a major city (compared to 28.2% of the general population), 33.6% were born outside Australia (compared to 33.3% of the general population), and 11.5% primarily speak a language other than English (compared to 22.2% of general population households where a non-English language is spoken) [22]. While comparable on sex, the ROSA dementia cohort is older at entry than other registries and includes more people living in permanent residential care.

Table 2. Comparison of the ROSA Dementia Cohort and International Dementia Registries, Demographic Characteristics

	ROSA Dementia Cohort *n*=313,544	Swedish Dementia Registry [12] *n*=28,722 [a]	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [13,23] *n*=193,729 [b]	Registry of Dementia for Girona [14] *n*=377	National Alzheimer's Coordinating Centre Unified Data Set [24] *n*=25,429
Age at cohort entry (x̄, SD)	83.6 (6.9)	79.3 (8.0)	AD: 81.9 (NA) Other: 79.3 (NA) MCI: 75.1 (NA)	78.9 (7.8)	Dementia: 75.9 (10.8) MCI: 75.7 (10.2)
<65 years	0 (0.0)	NA	NA	NA	Dementia: 2835 (15.7) MCI: 968 (13.1)
65-84 years	161,875 (51.6)	NA	NA	NA	Dementia: 11,220 (62.2) MCI: 4975 (67.4)
>=85 years	151,668 (48.4)	NA	NA	NA	Dementia: 3994 (22.1) MCI: 1437 (19.5)
Sex					
Female	189,928 (60.6)	16,994 (59.2)	123,138 (63.6)	361 (62.6)	24,023 (57.2)
Male	123,567 (39.4)	11,728 (40.8)	70,591 (36.4)	216 (37.4)	17,999 (42.8)
Living arrangements at entry			(*n*=341,498) [b]		
Lives alone	72,422 (23.1)	25,492 (88.8) [c]	32,034 (9.4)	505 (87.6) [c]	NA
Lives with family or others	127,548 (40.7)		240,967 (70.5)		NA
PRAC or other	113,574 (36.2)	3230 (10.2)	68,497 (20.1)	72 (12.5)	NA

Timeframes: ROSA July 2008-May 2016; SveDem 2007-2012; BNA 2010-2012; ReDeGi 2007; NACC UDS 2005-2015

AD=Alzheimer's disease; ROSA=Registry of Senior Australians; SD=Standard deviation.

[a] Figures published in 2015; the registry included 81,152 individuals in October 2018 (www.ucr.uu.se/svedem/)

[b] Includes 147,769 people with other diagnoses (psychiatric disorders, subjective memory complaints, other neurological disorders, diagnoses pending)

[c] Living in community

Alzheimer's disease (AD) is the most common type of dementia in ROSA, similarly to other registries examined (Table 3). On cognitive assessment, which are only completed by those living in permanent residential care (76% of the cohort had a PAS-CIS score available), the ROSA cohort were more cognitively impaired than the cohorts of other registries.

Table 3. Comparison of the ROSA Dementia Cohort and international dementia registries on clinical characteristics

	ROSA Dementia Cohort *n*=243,477 [a]	Swedish Dementia Registry [12] *n*=28,722	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [13,23] *n*=193,729	Registry of Dementia for Girona [14] *n*=577	National Alzheimer's Coordinating Centre Unified Data Set *n*=25,429 [25]
Dementia type					
Alzheimer's disease	177,209 (72.8)	9248 (32.2)	90,176 (46.5)	346 (60.0)	13,424 (52.8)
Vascular dementia	27,493 (11.3)	5199 (18.1)		27 (4.7)	446 (1.8)
Dementia in other diseases	9680 (3.8)	NA		40 (6.9)	
Mixed type	4366 (1.8)	5400 (18.8)	73,982 (38.2) [b]	62 (10.7)	4,179 (16.4) [d]
Other dementias (including unspecified)	22,637 (9.3)	8875 (31.1)		102 (17.7)	
Mild cognitive impairment	NA	NA	29,571 (15.3)	NA	7380 (29.0)
Missing	2092 (0.9)	NA	NA [c]	0 (0.0)	0 (0.0)
Cognitive impairment score mean (SD)	PAS-CIS [e] 11.7 (5.0)	MMSE 21.1 (5.1)	MMSE AD: 16.4 Other: 18.5 MCI: 25.6	MMSE 16.8 (6.4)	MMSE Dementia: 19.7 (6.9) MCI: 26.9 (2.5)
Cognitive impairment Category	PAS-CIS	MMSE	MMSE	CDRS	
No or minimal impairment	9336 (3.8)	NA	21,530 (11.1)	NA	NA
Mild impairment	55,535 (22.8)	NA (32.4)	62,371 (32.2)	350 (60.7)	NA
Moderate impairment	94,539 (38.8)	NA (36.3)	67,716 (35.0)	153 (26.5)	NA
Severe impairment	84,063 (34.5)	NA	17,402 (9.0)	53 (9.2)	NA
Missing	4 (0.0)	NA	24,710 (12.8)	21 (3.6)	NA

AD=Alzheimer's disease; CDRS=Clinical Dementia Rating Scale; MCI=Mild cognitive impairment; MMSE=Mini-mental Status Examination [17]; NA=Not available; PAS-CIS=Psychogeriatric Assessment Scales-Cognitive Impairment Scale; ROSA=Registry of Senior Australians; SD=Standard deviation.

[a] From residential care funding assessments (*n*=69,267 without these assessment data not included)

[b] Vascular dementia, dementia in other disease, mixed type, other dementias, unspecified dementia

[c] 'Diagnosis pending' *n*=69,355

[d] Dementia in other diseases + mixed + other + unspecified

[e] *n*=169,041, PAS-CIS at times not conducted due to severe cognitive impairment, speech impairments, language differences, sensory impairments, or refusal

People in the ROSA dementia cohort have a median four (interquartile range=2) other comorbid health conditions. In SveDem, people with dementia recorded a median Charlson comorbid index score of 2 (IQR=2) [26]. In the ROSA dementia cohort, the most common comorbid conditions were hypertension (54.3%), arthritis (51.6%), and heart diseases (48.5%). Cerebrovascular disease (22.1%) and hypercholesterolemia (15.6%) were common. Prevalence of hypertension was similar to both the Spanish ReDeGi (50.6%) and the US NACC UDS (35-87%) registries, while prevalence of hypercholesterolemia was lower than both of these registries (25.1% and 38-78%, respectively). Prevalence of cerebrovascular disease in our cohort was similar to ReDeGi [14]. In our cohort, more than 99% of individuals reported at least one activity limitation, most often transport (94.7%), health care tasks (92.7%) and social and community participation (92.5%). Individuals in the ROSA dementia cohort lived for an average of two years after they were first identified with dementia in the aged care assessment data and were on average 87 years (SD=6.6 years) at the time of their deaths. In contrast, a recent analysis of the SveDem cohort identified that only 28% of the cohort had died within the median 2-year follow up period [27]. In ROSA, dementia was recorded as the primary cause of death for 25% of the cohort, most commonly unspecified dementia (14.4%). Other common causes of death were heart diseases (21.9%) and cerebrovascular disease (11.7%).

FINDINGS TO DATE

To date, the ROSA dementia cohort has been used to demonstrate a declining prevalence of dementia in individuals entering the aged care sector [8], to determine that there is a higher prescribing of psychotropic medicines in people with dementia in residential care, to show the value of residential respite for delaying institutionalisation for people with dementia [28], and to highlight poorer outcomes after hip fracture among those with pre-morbid dementia than without dementia [29].

STRENGTHS AND LIMITATIONS

The large sample and national coverage provided by ROSA are key strengths of the ROSA dementia cohort. ROSA includes the largest existing population-based sample of people with dementia in Australia and is representative of the population in many ways, including sex, regionality, and cultural and linguistic diversity. An average of 37,661 new cases of dementia are identified in ROSA each year and many of these may not be identified via other sources. The ROSA dementia cohort is therefore a powerful resource both on its own and as a contributor to the ADNeT CQR [6]. A wide breadth of data is available in ROSA and this is expanding as linkage to new state-based data sources continues, including hospitalisations

and ambulance use. These data can facilitate monitoring of clinical care and determinants of important outcomes including institutionalisation and mortality over time.

Despite these benefits, there are important limitations to the ROSA dementia cohort. First, we cannot capture people with dementia who do not have a diagnosis, nor those who do not access aged care services. Approximately half of people with dementia in Australia are estimated to receive a diagnosis [7,30,31], and delays in diagnosis are common [7,32]. People who do receive a diagnosis tend to have more severe impairment, have insight into their impairment, speak English, live in metropolitan areas and in areas with greater access to health services, have higher levels of education, and be married [33]. Also, one in three women and one in two men will not use an aged care service in their lifetime [34]; ROSA is not able to capture these individuals and these factors introduce a sampling bias to our cohort.

Second, two important groups are not represented in the current ROSA cohort. People who accessed aged care services before 65 years of age but died before turning 65 years old are not included. We estimate that ROSA currently captures 40-84% of those aged under 65 using aged care (depending on the year). The number of missing cases of dementia attributable to this data gap is likely to be small given that most people with symptom onset prior to 65 years are aged 60-64 years at onset and will age over 65 years with their condition [35]. Nonetheless, types of dementia that are most common in younger groups (for example alcohol-related

dementias, frontotemporal dementias, dementia in Huntington's disease, dementia in Down syndrome) are likely to be underrepresented. ROSA also does not currently include Aboriginal and Torres Strait Islander people, though consultation is under way to enable inclusion of this cohort in future analyses.

Third, the data available in ROSA is not collected for research purposes and therefore may have limited internal validity. While the 'breadth' of data is a key strength of this cohort, its relative lack of 'depth' is a limitation and the suitability of service use is difficult to assess. The accuracy of clinical and demographic data also relies on assessors who are not necessarily trained in research data collection or in dementia care. Aged care assessors are limited to recording a maximum of 10 health conditions (ACAT) or three mental/cognitive conditions (ACFI) per assessment; whether dementia is considered an important enough comorbidity to be listed is at the assessors' discretion. In the absence of cognitive assessment, the accuracy of the dementia diagnosis recorded in ROSA is dependent on the skills and resources available to the clinician who made the diagnosis. Additionally, ROSA is not a dementia-specific registry and includes fewer clinical details than available in other cohorts.

Finally, aged care eligibility assessments can occur sometime after dementia symptom onset or formal diagnosis, limiting the potential for monitoring early clinical care. More than 36% of individuals entered the ROSA dementia cohort at entry to or while living in residential aged

care, which is likely to be late in their disease path. As such, people living in permanent residential care are overrepresented in ROSA compared to national estimates [5] and to other registries that recruit at the time of diagnosis. They are also likely to have more functional limitations and comorbid health conditions and to die sooner than other registries, though little data from other registries is available for comparison. Capture of those entering residential care for a dementia CQR is nonetheless important given that many will not be identified elsewhere.

COLLABORATION AND PATIENT AND PUBLIC INVOLVEMENT

ROSA is the product of a consortium of 13 academic, clinical, industry, consumer representative and public health organisations [9]. The consortium oversees ROSA management and use, ensuring that ROSA projects have clinical and public health relevance. Consumer representatives are part of the governance structure of ROSA, which provided oversight for ROSA's development and now ongoing operations. Results described here demonstrate that aged care assessment data can be a valuable resource for maximising capture for the ADNeT CQR. The ongoing collaboration between ROSA and ADNeT will ensure that people with dementia using aged care services can benefit from the ongoing monitoring and benchmarking of their clinical care.

AUTHOR CONTRIBUTIONS

MCI, MCr, and SW conceptualised the project, obtained funding, and assisted with reviewing and editing the manuscript. MCa drafted, reviewed, and edited the manuscript. MCa and CL conducted data analysis. CW and JM provided oversight to the project and assisted with manuscript review and editing. All authors read and approved the final manuscript.

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CONFLICTS OF INTEREST

MCa has been employed in the last five years to assist with data collection for drug trials funded by Janssen and Merck. All other authors declare no conflicts of interest.

ETHICAL APPROVAL

Ethical approval was provided by the University of South Australia (reference ID200489), Australian Institute of Health and Welfare (reference EO2018/1/418), South Australian Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South Wales Population and Health Services (reference 2019/ETH12028) Human Research Ethics Committees.

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SUPPLEMENTARY MATERIALS

Supplementary Table 1. The ROSA Dementia Cohort Comprehensive Demographic and Clinical Characteristics

		n (%)
		All (*n*=313,544)
Age at cohort entry (mean, SD)		83.6 (6.9)
	65-69	10,696 (3.4)
	70-79	69,937 (22.3)
	80-89	171,447 (54.7)
	>89	61,464 (19.6)
Sex		
	Female	189,928 (60.6)
	Male	123,567 (39.4)
	Missing	49 (0.1)
Country of birth		
	Australia	206,014 (65.7)
	Outside Australia	105,460 (33.6)
	Missing	2070 (0.7)
Language		
	English	275,684 (87.9)
	Other	36,143 (11.5)
	Missing	1717 (0.6)
State		
	New South Wales	108,066 (34.5)
	Victoria	78,086 (24.9)
	Queensland	53,110 (16.9)
	Western Australia	30,916 (9.9)
	South Australia	28,195 (9.0)
	Tasmania	7847 (2.5)
	Northern Territory	678 (0.2)
	Australian Capital Territory	3481 (1.1)
	Missing	3165 (1.0)
ARIA Region [a]		
	Major city	207,112 (66.1)
	Inner regional	66,043 (21.1)
	Outer regional	31,580 (10.1)
	Remote	3457 (1.1)
	Very remote	1133 (0.4)
	Missing	4219 (1.4)
Socio-economic status (derived from postcode using IRSD)		
	Most Disadvantaged -1	52,609 (16.8)
	2	54,129 (17.3)
	3	55,562 (17.7)
	4	59,173 (18.9)
	Least Disadvantaged- 5	87,830 (28.0)
	Missing	4241 (1.4)
Marital status		
	Married	117,826 (37.6)
	Separated or divorced	19,931 (6.4)
	Widowed	141,147 (45.0)
	Never married	13,907 (4.4)
	Missing	20,733 (6.6)
Carer availability [b] (*n*=214,794)		
	Has carer	185,144 (86.2)
	No carer	14,785 (6.9)
	Missing	14,865 (6.9)

	n (%)
	All (*n*=313,544)
Carer relationship [b] (*n*=185,144)	
Spouse	80,103 (43.3)
Parent	164 (0.09)
Child or child-in-law	88,117 (47.6)
Other relative	10,077 (5.4)
Friend/neighbour	5968 (3.2)
Missing	715 (0.4)
Carer co-residency [b] (*n*=185,144)	117,634 (63.6)
Dementia identified	
Medicine dispensing only	3515 (1.1)
ACAP or medicine dispensing only	68,644 (21.9)
ACFI or medicine dispensing only	101,149 (32.3)
Both ACAP and ACFI	140,236 (44.7)
Dementia first identified using [c]	
ACAP	210,658 (67.2)
ACFI	102,886 (32.8)
Year dementia first recorded in aged care records	
2008	34,134 (10.9) [d]
2009	48,494 (15.5)
2010	36,654 (11.7)
2011	36,125 (11.5)
2012	36,247 (11.6)
2013	36,097 (11.5)
2014	36,674 (11.7)
2015	36,892 (11.8)
2016	12,227 (3.9) [e]
Number Medical Conditions (median, IQR) [f]	4 (4-6)
0	22,604 (7.2)
1-4	144,911 (46.2)
5-9	133,556 (42.6)
10+	12,473 (4.0)
Activity limitations [b] (*n*=214,794)	
None	405 (0.2)
Communication	66,759 (31.1)
Domestic assistance	190,672 (88.8)
Health care tasks	199,194 (92.7)
Home maintenance	161,242 (75.1)
Meals	186,420 (87.0)
Movement activities	60,541 (28.2)
Moving around places	139,503 (65.0)
Self-care	164,471 (76.6)
Transport	203,425 (94.7)
Social and community participation	198,772 (92.5)
Other	12,486 (5.8)
Most common co-morbidities [b] (*n*=214,794)	
Hypertension	116,780 (54.3)
Arthritis (rheumatoid and other)	110,911 (51.6)
Heart diseases	104,357 (48.5)
Falls	55,686 (25.9)
Cerebrovascular disease	47,417 (22.1)
Diabetes – type 2	47,415 (22.1)
Abnormalities of gait and mobility	46,799 (21.8)
Osteoporosis	45,957 (21.4)
Deafness/hearing loss	38,858 (18.1)
Hypercholesterolemia	33,474 (15.6)

	n (%)
	All (*n*=313,544)
Cornell Scale for Depression [g] (*n*=78,400) (mean, SD)	12.2 (6.6)
Dead at May 31 2016	191,721 (61.2)
Age at death (*n*=191,721) (mean, SD)	87.0 (6.6)
Years from cohort entry to death (*n*=191,721) (mean, SD)	2.0 (1.7)
Primary cause of death (*n*=191,721)	
Circulatory disease	66,661 (34.8)
Heart disease	42,008 (21.9)
Cerebrovascular disease	22,399 (11.7)
Dementias	47,810 (24.9)
Unspecified dementia	27,552 (14.4)
Alzheimer's disease	15,070 (7.9)
Vascular dementia	5188 (2.7)
Respiratory disease (including pneumonia)	15,350 (8.0)
Other causes	61,900 (32.3)

ACAP=Aged Care Assessment Program; ACFI=Aged Care Funding Instrument; ARIA=Accessibility/Remoteness Index of Australia; IQR=Interquartile range; IRSD=Index of Relative Socio-Economic Disadvantage; SD=Standard deviation

[a] Remoteness categories are from the Accessibility/Remoteness Index of Australia Plus (ARIA+) 2016. These have also been linked to the cohort based on the postcode at the time of the assessment.

[b] From ACAP recordings – includes ACAP data for *n*=4,136 individuals who entered the ROSA dementia cohort from an earlier ACFI assessment.

[c] Or medicine dispensing closest to one of these

[d] From July 2008

[e] To May 2016

[f] From RxRisk, medicine-based comorbidity measure

[g] From ACFI recordings at cohort entry

BMJ Open

Cohort profile: Dementia in the Registry of Senior Australians

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TITLE

Cohort profile: Dementia in the Registry of Senior Australians

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ABSTRACT

Purpose

Clinical quality registries (CQR) are being established in many countries to monitor, benchmark, and report on the quality of dementia care over time. Case ascertainment can be challenging given that diagnosis occurs in a variety of settings. The Registry of Senior Australians (ROSA) includes a large cohort of people with dementia from all Australian states and territories identified using routinely-collected aged care assessment data. In ROSA, assessment data is linked to information about aged and health service use, medicine dispensing, hospitalisations, and the National Death Index. The ROSA dementia cohort was established to capture people for the Australian dementia CQR currently in development who may not be identified elsewhere.

Participants

There were 373,695 people with dementia identified in aged care assessments from 2008 to 2016. Individuals were 84.1 years old on average at cohort entry (e.g. when first identified with dementia on an aged care assessment), and 63.1% were female. More than 44% were first identified at entry to permanent residential aged care. The cohort recorded more severe cognitive impairment than other international dementia registries.

Findings to date

The cohort has so far been used to demonstrate a declining prevalence of dementia in individuals entering the aged care sector, examine trends in psychotropic medicine prescribing, and to examine the impact of dementia on aged care service use and outcomes.

Future plans

The ROSA dementia cohort will be updated periodically and is a powerful resource both on its own and as a contributor to the Australian dementia CQR. Integration of the ROSA dementia cohort with the dementia CQR will ensure that people with dementia using aged care services can benefit from the ongoing monitoring and benchmarking of care that a registry can provide.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The ROSA dementia cohort includes large cohort of people with dementia from all Australian states and territories, with a wide breadth of linked data to allow for monitoring of care.
- The ROSA dementia cohort does not include people who do not have a diagnosis of dementia or those who have not used government-subsidised aged care services.
- Entry to the ROSA dementia cohort occurs at identification on aged care eligibility assessments, which can be sometime after dementia symptom onset or formal diagnosis. This limits the potential for monitoring early clinical care.

INTRODUCTION

Registries are powerful tools for research and monitoring of clinical care because they facilitate population-level surveillance over time [1,2]. As the global prevalence of dementia rises [3], dementia-related registries are being established internationally to complement clinical research and improve the quality of care for people with this condition [4]. Methods of capturing cases of dementia vary between registries but usually include reporting from specialist clinics and hospitals. Importantly for a dementia registry, diagnosis occurs in a variety of settings and therefore capturing the whole population can be challenging [4].

Dementia is a common chronic health condition in Australia, affecting an estimated one in 10 people aged over 65 years [5]. More than 400,000 people are estimated to be living with dementia in Australia, 25,000 of whom are aged under 65 years [5]. The Australian Dementia Network (ADNeT) Clinical Quality Registry (CQR) is a new national dementia CQR established to monitor, benchmark, and report on the quality of care for people with mild cognitive impairment (MCI) and dementia over time [6]. The ADNeT Registry enrols participants at the point of diagnosis in memory or private specialist clinics and will track longitudinal outcomes via patient and carer reported outcome measures as well as linkage with administrative datasets.

However, many people with dementia or MCI may be diagnosed in other settings [7]. Given the high prevalence of dementia among those accessing government-subsidised aged care services [8], existing aged care assessment data has great potential to contribute to the capture of individuals into the ADNeT CQR. Approximately 47% of Australian residential care users and 21% of home care users have a recorded diagnosis of dementia [8]. It is estimated that aged care assessments conducted from 2009 to 2015 captured approximately 36% of the estimated total population of people with dementia in Australia (prevalent cases) at the end of 2015 [9]. Therefore, understanding and studying the cohort with dementia captured within the aged care sector can significantly contribute to our understanding of the individuals that may not be captured earlier for a national CQR. Information about health service use, medicines, hospitalisations, mortality and other information can then be monitored for these individuals over time.

In our current evaluation we have examined (a) the demographic and clinical features of people with dementia using Australian aged care services and the extent to which these are representative of the broader population of people with dementia in Australia, and (b) the comparability of data captured in aged care datasets to selected established international dementia registries. This will allow for better understanding of the characteristics and

limitations of this cohort for monitoring the quality of care and outcomes for people living with dementia in Australia.

COHORT DESCRIPTION

Design and data sources

A national cohort of all non-Indigenous Australians aged 65 and over who have accessed government-subsidised aged care services from 1997 to 2017 (and updated regularly) is captured in the Registry of Senior Australians (ROSA). In ROSA, national aged care assessment data are linked with information about aged care service use, health service use, medication dispensing, hospitalisations, and death records [10] of individuals that entered the aged care sector. Specifically, assessments within the aged care sector are conducted to determine eligibility for government-subsidised services (by Aged Care Assessment Teams, established in 2003; ACAT) or to identify funding requirements in residential aged care (Aged Care Funding Instrument, established in 2008; ACFI). In both assessments assessors are clinically-trained medical, nursing or allied health professionals who identify the level of care need based on functional and cognitive limitations [11,12]. Data from assessments, as well as aged care service use, are provided to ROSA from the Australian Institute of Health and Welfare National Aged Care Data Clearinghouse.

These data are subsequently linked with information about government-subsidised health service use from the Medicare Benefits Schedule (MBS), medicine dispensing from the Pharmaceutical Benefits Scheme (PBS), state based hospital records and mortality data from the National Death Index (NDI). The ROSA established this cross-sector data linkage for research purposes and aims to assess the effectiveness, appropriateness, and quality of aged care services provided to older individuals over time. In its entirety, the historical ROSA cohort includes over 2.8 million individuals, including 1.2 million who have had aged care eligibility assessments for substantial aged care services like permanent residential care, home care packages, residential respite care and transition care.

Ethical approval for ROSA was provided by the University of South Australia (reference ID200489), Australian Institute of Health and Welfare (reference EO2018/1/418), South Australian Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South Wales Population and Health Services (reference 2019/ETH12028) Human Research Ethics Committees.

Here we present results of a cross-sectional evaluation of the people with dementia identified in aged care assessment data (hereafter referred to as the 'ROSA dementia cohort') between July 1 2008 and June 30 2016. The entry point to the ROSA dementia cohort is the first aged care assessment where a recording of dementia was made, though the person may have

entered the ROSA with an earlier assessment (on which a dementia diagnosis was not recorded). Entry is distinct from the date of diagnosis, which will have occurred earlier and is not known for our cohort. Where a person is identified from medication prescribing records, data from the closest aged care assessment is included here for cohort profiling.

Dementia ascertainment

Dementia is determined from aged care eligibility assessments (conducted by ACAT), assessments for funding in permanent residential care (conducted using the ACFI), and from pharmaceutical data as captured in PBS. In assessments, assessors record up to 10 (ACAT) or up to three (ACFI) major diseases or disorders that have an impact on the person's need for assistance with activities of daily living and social participation, together with documented evidence of a diagnosis from a medical practitioner. Assessors can record one or more types of dementia or have the option to classify the dementia as 'unspecified' based on the medical record. In addition, medicines prescribed for the treatment of Alzheimer's disease are not dispensed for any other reason. Any person with who has been dispensed donepezil (Anatomical Therapeutic Chemical Classification System code, ATC N06DA02), galantamine (ATC code N06DA04), rivastigmine (ATC code N06DA03) or memantine (ATC code N06DX01) can be classified as having dementia.

Minimum data set

The data available for the ROSA dementia cohort is presented in Table 1, with comparable data from other established dementia registries. Registries included for comparison were chosen based on their broad coverage and the availability of data for comparison here. They include one clinical quality registry (the Swedish Dementia Registry (SveDem)), and two epidemiological dementia registries (French National Alzheimer Database (BNA); Registry of Dementia of Girona, Spain (ReDeGi)).

148 Table 1. Comparison of the ROSA Dementia Cohort and International Dementia Registries, Minimum Dataset Available

	ROSA Dementia Cohort	Swedish Dementia Registry [13]	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14]	Registry of Dementia for Girony [15]
Country	Australia	Sweden	France	Spain [a]
Demographics	Date of birth Sex Living arrangements Country of birth Language Region Marital status Socioeconomic status [b] Carer availability Carer relationship Carer co-residency (y/n)	Age Sex Living arrangements Driver's licence (y/n) Weapons licence (y/n)	Date of birth Sex Living arrangements Area of birth Education	Date of birth Sex Living arrangement Nationality Region Occupation Education Marital status
Clinical characteristics	Type of dementia	Type of dementia Family history of dementia BMI Total number of diagnostic tests	Type of dementia Procedure type [c]	Type of dementia Family history of dementia Aged at symptom onset (estimated) Date of diagnosis

		Time needed for diagnosis Recommended diagnostic workup (y/n)		
Cognitive testing	PAS-CIS score [d]	MMSE score	MMSE score	MMSE score BDRS score CDRS score
Care use	All government funded aged care (inc. dates and priority) including: • Respite care • Home care • PRAC • Transition care • Other home and community support services Health service use [e]	Respite care (y/n) Home care (y/n) PRAC (date of moving, type of home) [a]	Date of entry to residential care Psychosocial intervention (yes/no)	NA
Medications	All (including dosage and dates) [f]	Anti-dementia (y/n) Antidepressants (y/n) Antipsychotics (y/n) Anxiolytics (y/n) Hypnotics (y/n)	Anti-dementia (y/n) Antidepressants (y/n) Antipsychotics (y/n) Anxiolytics (y/n) Hypnotics (y/n)	Anti-dementia (y/n) Antidepressants (y/n) Antipsychotics (y/n)

		Cardiovascular drugs (y/n) Total number of drugs	Serious drug-related adverse event (y/n)	
Health and wellbeing	Comorbidities [g] Cornell Scale for Depression in Dementia [d]	QUALID [d] Falls, ulcers, malnutrition, oral health (screening and intervention) [d] Links to other registries		Present hypertension, diabetes mellitus, dislipidemia, stroke, thyroid disease History of depression
Function	Activity limitations	IADL score [a]	IADL score	
Death	Date of death Causes of death	Time to death (months)	Date of death	NA

BDRS=Blessed Dementia Rating Scale ; BMI=Body mass index; CDRS=Clinical Dementia Rating Scale; IADL=Instrumental Activities of Daily Living [16]; MMSE=Mini-mental Status Examination [17]; NA=Not available;; PAS-CIS=Psychogeriatric Assessment Scale-Cognitive Impairment Scale; PRAC=Permanent residential aged care; QUALID=Quality of Life in Late-Stage Dementia scale [18]; SD=Standard deviation.

[a] Regional only - Girona

[b] Measured using the Index of Relative Socio-economic Disadvantage compiled by the Australian Bureau of Statistics

[c] Consultation, neuropsychological assessment, day-hospital visit, or group session

[d] PRAC only

[e] Government-subsidised health care services only (i.e. not privately funded), including hospitalisation, emergency department, and ambulance service records for some states.

[f] Government-subsidised medicines only

[g] 204 possible comorbidities recorded by assessors or 46 captured from a medication-based co-morbidity measure

ROSA includes comprehensive demographic data and information about aged and health care service use, including service entry and exit dates. All prescription-based medicine dispensing is recorded by the PBS, facilitating monitoring of medicine dosage, duration, and polypharmacy. Information about family history of dementia, diagnostic procedures, or other clinical details (aside from comorbidities) is not available. ROSA also does not include privately-funded health service use.

Assessments conducted for financial purposes at entry into residential aged care are repeated when care needs change. These include a standardised neuropsychological assessment. While most dementia registries include the Mini-Mental Status Examination (MMSE), copyright restrictions have precluded its widespread clinical use in Australia. Instead, the Psychogeriatric Assessment Scale-Cognitive Impairment Scale (PAS-CIS) [19] is conducted where cognitive impairment is suspected or known. The PAS-CIS correlates strongly with the MMSE [20]. A Cornell Scale for Depression (CSD) [21] is conducted where symptoms of depression and dysthymia are present. Functional dependence is rated across domains (including nutrition, mobility, personal hygiene, toileting, continence, home maintenance, and transport) though a validated measure like those used in other registries is not included.

Cohort characteristics

There were 363,695 people in the ROSA dementia cohort over the capture period (Table 2). Detailed demographic data on the cohort appears in Supplementary Table 1. The cohort is representative of the geographical spread of the Australian population with the majority living in New South Wales, Victoria, and Queensland (76.2%, compared to 77.4% of the general population). Similarly, 33.4% of the ROSA dementia cohort live outside a major city (compared to 28.2% of the general population), 32.9% were born outside Australia (compared to 33.3% of the general population), and 11.5% primarily speak a language other than English (compared to 22.2% of general population households where a non-English language is spoken) [22]. While comparable on sex, the ROSA dementia cohort is older at entry than other registries and includes more people living in permanent residential care.

Table 2. Comparison of the ROSA Dementia Cohort and International Dementia Registries, Demographic Characteristics

	ROSA Dementia Cohort *n*=373,695	Swedish Dementia Registry [13] *n*=28,722 [a]	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14,23] *n*=193,729 [b]	Registry of Dementia for Girona [15] *n*=377
Age at cohort entry (x̄, SD)	84.1 (6.9)	79.3 (8.0)	AD: 81.9 (NA) Other: 79.3 (NA) MCI: 75.1 (NA)	78.9 (7.8)
65-69 years	11,181 (3.0)	NA	NA	NA
70-79 years	78,409 (21.0)	NA	NA	NA
80-89 years	202,519 (54.2)	NA	NA	NA
90+ years	81,586 (21.8)	NA	NA	NA
Sex				
Female	235,703 (63.1)	16,994 (59.2)	123,138 (63.6)	361 (62.6)
Male	137,943 (36.9)	11,728 (40.8)	70,591 (36.4)	216 (37.4)
Missing	49 (0.1)	NA	NA	NA
Living arrangements at entry			(*n*=341,498) [b]	
Lives alone	72,392 (19.4)	25,492 (88.8) [c]	32,034 (9.4)	505 (87.6) [c]
Lives with family or others	134,943 (36.1)		240,967 (70.5)	
PRAC or other	166,349 (44.5)	3230 (10.2)	68,497 (20.1)	72 (12.5)

Timeframes: ROSA July 2008-May 2016; SveDem 2007-2012; BNA 2010-2012; ReDeGi 2007

AD=Alzheimer's disease; ROSA=Registry of Senior Australians; SD=Standard deviation.

[a] Figures published in 2015; the registry included 81,152 individuals in October 2018 (www.ucr.uu.se/svedem/)

[b] Includes 147,769 people with other diagnoses (psychiatric disorders, subjective memory complaints, other neurological disorders, diagnoses pending)

[c] Living in community

Alzheimer's disease (AD) is the most common type of dementia in ROSA, similarly to other registries examined (Table 3). On cognitive assessment, which are only completed by those living in permanent residential care (82% of the cohort had a PAS-CIS score available), the ROSA cohort were more cognitively impaired than the cohorts of other registries.

199 Table 3. Comparison of the ROSA Dementia Cohort and international dementia registries on clinical characteristics

	ROSA Dementia Cohort *n*=309,958 [a]	Swedish Dementia Registry [13] *n*=28,722	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14,23] *n*=193,729	Registry of Dementia for Girona [15] *n*=577
Dementia type				
Alzheimer's disease	229,104 (73.9)	9248 (32.2)	90,176 (46.5)	346 (60.0)
Vascular dementia	33,638 (10.9)	5199 (18.1)		27 (4.7)
Dementia in other diseases	12,271 (4.0)	NA		40 (6.9)
Mixed type	5310 (1.7)	5400 (18.8)	73,982 (38.2) [b]	62 (10.7)
Other dementias (including unspecified)	27,621 (8.9)	8875 (31.1)		102 (17.7)
Mild cognitive impairment	NA	NA	29,571 (15.3)	NA
Missing	2374 (0.8)	NA	NA [c]	0 (0.0)
Cognitive impairment score mean (SD)	PAS-CIS [d] 12.0 (5.1)	MMSE 21.1 (5.1)	MMSE AD: 16.4 Other: 18.5 MCI: 25.6	MMSE 16.8 (5.4)
Cognitive impairment Category	PAS-CIS	MMSE	MMSE	CDRS
No or minimal impairment	7614 (3.6)	NA	21,530 (11.1)	NA
Mild impairment	60,347 (28.4)	NA (32.4)	62,371 (32.2)	350 (60.7)
Moderate impairment	86,742 (40.9)	NA (36.3)	67,716 (35.0)	153 (26.5)
Severe impairment	57,453 (27.1)	NA	17,402 (9.0)	53 (9.2)
Missing	0 (0.0)	NA	24,710 (12.8)	21 (3.6)

AD=Alzheimer's disease; CDRS=Clinical Dementia Rating Scale; MCI=Mild cognitive impairment; MMSE=Mini-mental Status Examination [17]; NA=Not available; PAS-CIS=Psychogeriatric Assessment Scales-Cognitive Impairment Scale; ROSA=Registry of Senior Australians; SD=Standard deviation.

[a] From residential care funding assessments (*n*=63,737 without these assessment data not included)

[b] Vascular dementia, dementia in other disease, mixed type, other dementias, unspecified dementia

[c] 'Diagnosis pending' *n*=69,355

[d] *n*=212,156; PAS-CIS at times not conducted due to severe cognitive impairment, speech impairments, language differences, sensory impairments, or refusal

People in the ROSA dementia cohort have a median four (interquartile range=2) other comorbid health conditions. In SveDem, people with dementia recorded a median Charlson comorbid index score of 2 (IQR=2) [24]. In the ROSA dementia cohort, the most common comorbid conditions were hypertension arthritis (35.0%), hypertension (34.9%), and heart diseases (31.7%%). Cerebrovascular disease (15.5%) and hypercholesterolemia (9.1%) were common. Prevalence of hypertension and hypercholesterolemia were lower than the Spanish ReDeGi registry (50.6% and 25.1%, respectively) ,). Prevalence of cerebrovascular disease in our cohort was similar to ReDeGi [15]. In our cohort, more than 99% of individuals reported at least one activity limitation, most often transport (94.7%), health care tasks (92.7%) and social and community participation (92.5%). Individuals in the ROSA dementia cohort lived for an average of two years after they were first identified with dementia in the aged care assessment data and were on average 88 years old (SD=6.6 years) at the time of their deaths. In contrast, a recent analysis of the SveDem cohort identified that only 28% of the cohort had died within the median 2-year follow up period [25]. In ROSA, dementia was recorded as the primary cause of death for 27% of the cohort, most commonly unspecified dementia (15.2%). Other common causes of death were heart diseases (21.8%) and cerebrovascular disease (21.1%).

Patient and Public Involvement

Consumer representatives are part of the governance structure of ROSA, and provided oversight for ROSA's development and now oversee ongoing operations.

FINDINGS TO DATE

To date, the ROSA dementia cohort has been used to demonstrate a declining prevalence of dementia in individuals entering the aged care sector [8], to determine that there is a higher prescribing of psychotropic medicines in people with dementia in residential care, to show the value of residential respite for delaying institutionalisation for people with dementia [26], and to highlight poorer outcomes after hip fracture among those with pre-morbid dementia than without dementia [27]. The broader ROSA dataset has also recently been used to develop an Outcome Monitoring System for aged care, with 12 indicators of care quality that can be monitored over time and across geographical areas [28]. Most of these indicators are relevant to dementia care, including psychotropic medicine use, hospitalisations, and falls, and work is underway to apply them to the monitoring of care in the ROSA dementia cohort.

STRENGTHS AND LIMITATIONS

The large sample and national coverage provided by ROSA are key strengths of the ROSA dementia cohort. ROSA includes the largest existing population-based sample of people with dementia in Australia and is representative of the population in many ways, including sex,

regionality, and cultural and linguistic diversity. An average of 37,661 new cases of dementia are identified in ROSA each year and many of these may not be identified via other sources [9]. The ROSA dementia cohort is therefore a powerful resource both on its own and as a contributor to the ADNeT CQR [6]. A wide breadth of data is available in ROSA and this is expanding as linkage to new state-based data sources continues, including hospitalisations and ambulance use. These data can facilitate monitoring of clinical care and determinants of important outcomes including institutionalisation and mortality over time.

Despite these benefits, there are important limitations to the ROSA dementia cohort. First, we cannot capture people with dementia who do not have a diagnosis, nor those who do not access aged care services. Approximately half of people with dementia in Australia are estimated to receive a diagnosis [7,29,30], and delays in diagnosis are common [7,31]. People who do receive a diagnosis tend to have more severe impairment, have insight into their impairment, speak English, live in metropolitan areas and in areas with greater access to health services, have higher levels of education, and be married [32]. Also, one in three women and one in two men will not use an aged care service in their lifetime [33]; ROSA is not able to capture these individuals and these factors introduce a sampling bias to our cohort.

Second, two important groups are not represented in the current ROSA cohort. People who accessed aged care services before 65 years of age but died before turning 65 years old are

not included. We estimate that ROSA currently captures 40-84% of those aged under 65 using aged care (depending on the year). The number of missing cases of dementia attributable to this data gap is likely to be small given that most people with symptom onset prior to 65 years are aged 60-64 years at onset and will age over 65 years with their condition [34]. Nonetheless, types of dementia that are most common in younger groups (for example alcohol-related dementias, frontotemporal dementias, dementia in Huntington's disease, dementia in Down syndrome) are likely to be underrepresented. ROSA also does not currently include Aboriginal and Torres Strait Islander people, though consultation is under way to enable inclusion of this cohort in future analyses.

Third, the data available in ROSA is not collected for research purposes and therefore may have limited internal validity. While the 'breadth' of data is a key strength of this cohort, its relative lack of 'depth' is a limitation and the suitability of service use is difficult to assess. The accuracy of clinical and demographic data also relies on assessors who are not necessarily trained in research data collection or in dementia care. Aged care assessors are limited to recording a maximum of 10 health conditions (ACAT) or three mental/cognitive conditions (ACFI) per assessment; whether dementia is considered an important enough comorbidity to be listed is at the assessors' discretion. In the absence of cognitive assessment, the accuracy of the dementia diagnosis recorded in ROSA is dependent on the skills and resources

available to the clinician who made the diagnosis. Additionally, ROSA is not a dementia-specific registry and includes fewer clinical details than available in other cohorts.

Finally, aged care eligibility assessments can occur sometime after dementia symptom onset or formal diagnosis, limiting the potential for monitoring early clinical care. More than 36% of individuals entered the ROSA dementia cohort at entry to or while living in residential aged care, which is likely to be late in their disease path. As such, people living in permanent residential care are overrepresented in ROSA compared to national estimates [5] and to other registries that recruit at the time of diagnosis. They are also likely to have more functional limitations and comorbid health conditions and to die sooner than other registries, though little data from other registries is available for comparison. Capture of those entering residential care for a dementia CQR is nonetheless important given that many will not be identified elsewhere.

COLLABORATION

ROSA is the product of a consortium of 13 academic, clinical, industry, consumer representative and public health organisations [10]. The consortium oversees ROSA management and use, ensuring that ROSA projects have clinical and public health relevance. Results described here demonstrate that aged care assessment data can be a valuable

resource for maximising capture for the ADNeT CQR. Linkage between ROSA and ADNeT will ensure both that monitoring of care can occur early in the disease course, and that people with dementia using aged care services can benefit from the ongoing monitoring and benchmarking of their clinical care.

AUTHOR CONTRIBUTIONS

MC, MCr, and SW conceptualised the project, obtained funding, and assisted with reviewing and editing the manuscript. MCa drafted, reviewed, and edited the manuscript. MCa and CL conducted data analysis. CW and JM provided oversight to the project and assisted with manuscript review and editing. All authors read and approved the final manuscript.

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preparation of this manuscript. All authors had final responsibility for the decision to submit for publication.

CONFLICTS OF INTEREST

MCa has been employed in the last five years to assist with data collection for drug trials funded by Janssen and Merck. All other authors declare no conflicts of interest.

ETHICAL APPROVAL

Ethical approval was provided by the University of South Australia (reference ID200489), Australian Institute of Health and Welfare (reference EO2018/1/418), South Australian Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South Wales Population and Health Services (reference 2019/ETH12028) Human Research Ethics Committees.

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DATA AVAILABILITY STATEMENT

Researchers interested in collaboration are invited to contact the research team to access the data available in ROSA. In addition to the data described here, similar data is available from aged care users without dementia, and state-based hospitalisation data for some Australian states. Data linkage is ongoing and is being updated over time.

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SUPPLEMENTARY MATERIALS

Supplementary Table 1. The ROSA Dementia Cohort Comprehensive Demographic and Clinical Characteristics

		n (%)
		All (*n*=373,695)
Age at cohort entry (mean, SD)		84.1 (6.9)
	65-69	11,181 (3.0)
	70-79	78,409 (21.0)
	80-89	202,519 (54.2)
	>89	81,586 (21.8)
Sex		
	Female	235,703 (63.1)
	Male	137,943 (36.9)
	Missing	49 (0.1)
Country of birth		
	Australia	348,396 (66.5)
	Outside Australia	123,009 (32.9)
	Missing	2290 (0.6)
Language		
	English	329,108 (88.1)
	Other	42,779 (11.5)
	Missing	1808 (0.5)
State		
	New South Wales	127,830 (34.2)
	Victoria	92,911 (24.9)
	Queensland	63,986 (17.1)
	Western Australia	35,689 (9.6)
	South Australia	34,252 (9.2)
	Tasmania	9379 (2.5)
	Northern Territory	780 (0.2)
	Australian Capital Territory	4114 (1.10)
	Missing	4754 (1.3)
ARIA Region [a]		
	Major city	245,083 (65.6)
	Inner regional	78,320 (21.0)
	Outer regional	37,378 (10.0)
	Remote	4074 (1.1)
	Very remote	1307 (0.4)
	Missing	7533 (2.0)
Socio-economic status (derived from postcode using IRSD)		
	Most Disadvantaged -1	61,573 (16.5)
	2	63,830 (17.1)
	3	65,613 (17.6)
	4	70,050 (18.8)
	Least Disadvantaged- 5	105,029 (18.8)
	Missing	7600 (2.0)
Marital status		
	Married	133,647 (35.8)
	Separated or divorced	23,727 (6.3)
	Widowed	176,949 (47.4)
	Never married	17,950 (4.8)
	Missing	21,412 (5.7)
Carer availability [b] (*n*=214,780)		
	Has carer	185,118 (86.2)
	No carer	14,781 (6.9)
	Missing	14,836 (6.9)

	n (%)
	All (*n*=373,695)
Carer relationship [b] (*n*=185,118)	
Spouse	80,094 (43.3)
Parent	164 (0.9)
Child or child-in-law	88,105 (47.6)
Other relative	10,075 (5.4)
Friend/neighbour	5967 (3.2)
Missing	676 (0.4)
Carer co-residency [b] (*n*=185,118)	117,617 (63.5)
Dementia identified	
Medicine dispensing only	3694 (1.0)
ACAP or medicine dispensing only	62,417 (16.7)
ACFI or medicine dispensing only	161,135 (43.1)
Both ACAP and ACFI	146,449 (39.2)
Dementia first identified using [c]	
ACAP	207,346 (55.5)
ACFI	166,349 (44.5)
Number Medical Conditions (median, IQR) [f]	4 (4-6)
0	11,862 (3.2)
1-4	170,826 (45.7)
5-9	151,358 (40.5)
10+	13,747 (3.7)
Missing	25,875 (6.9)
Activity limitations [b] (*n*=214,780)	
None	405 (0.2)
Communication	66,745 (31.1)
Domestic assistance	190,642 (88.8)
Health care tasks	199,163 (92.7)
Home maintenance	161,220 (75.1)
Meals	186,390 (86.8)
Movement activities	60,528 (28.2)
Moving around places	139,482 (64.9)
Self-care	164,446 (76.6)
Transport	203,395 (94.7)
Social and community participation	198,743 (92.5)
Other	12,478 (5.8)
Most common co-morbidities at cohort entry	
Arthritis (rheumatoid and other)	130,824 (35.0)
Hypertension	130,569 (34.9)
Heart diseases	118,274 (31.7)
Falls	58,136 (15.6)
Cerebrovascular disease	57,772 (15.5)
Osteoporosis	54,555 (14.6)
Diabetes – type 2	54,026 (14.5)
Abnormalities of gait and mobility	48,151 (12.9)
Deafness/hearing loss	41,480 (11.1)
Hypercholesterolemia	14,043 (9.1)
Cornell Scale for Depression [g] (*n*=122,253) (mean, SD)	11.7 (6.7)
Dead at June 30 2016	249.682 (66.8)
Age at death (*n*=249,682) (mean, SD)	87.5 (6.6)
Years from cohort entry to death (*n*=249,682) (mean, SD)	2.1 (1.7)
Primary cause of death (*n*=249,682)	
Circulatory disease	87,604 (35.1)
Heart disease	54,412 (21.8)
Cerebrovascular disease	30,246 (21.1)

	n (%)
	All (*n*=373,695)
Dementias	66,287 (26.5)
Unspecified dementia	38,019 (15.2)
Alzheimer's disease	21,090 (8.4)
Vascular dementia	7178 (2.9)
Respiratory disease (including pneumonia)	19,675 (7.9)
Other causes	76,116 (30.5)

ACAP=Aged Care Assessment Program; ACFI=Aged Care Funding Instrument; ARIA=Accessibility/Remoteness Index of Australia; IQR=Interquartile range; IRSD=Index of Relative Socio-Economic Disadvantage; SD=Standard deviation

[a] Remoteness categories are from the Accessibility/Remoteness Index of Australia Plus (ARIA+) 2016. These have also been linked to the cohort based on the postcode at the time of the assessment.

[b] From ACAP recordings – includes ACAP data for *n*=7,434 individuals who entered the ROSA dementia cohort from an earlier ACFI assessment.

[c] Or medicine dispensing closest to one of these

[d] From July 2008

[e] To June 2016

[f] From RxRisk, medicine-based comorbidity measure

[g] From ACFI recordings – includes ACFI data (at entry to permanent residential aged care) for some individuals who entered the ROSA dementia cohort from an earlier ACAT assessment

BMJ Open

Cohort profile: Dementia in the Registry of Senior Australians

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TITLE

Cohort profile: Dementia in the Registry of Senior Australians

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ABSTRACT

Purpose

Clinical quality registries (CQR) are being established in many countries to monitor, benchmark, and report on the quality of dementia care over time. Case ascertainment can be challenging given that diagnosis occurs in a variety of settings. The Registry of Senior Australians (ROSA) includes a large cohort of people with dementia from all Australian states and territories identified using routinely-collected aged care assessment data. In ROSA, assessment data is linked to information about aged and health service use, medicine dispensing, hospitalisations, and the National Death Index. The ROSA dementia cohort was established to capture people for the Australian dementia CQR currently in development who may not be identified elsewhere.

Participants

There were 373,695 people with dementia identified in aged care assessments from 2008 to 2016. Cross-sectional analysis from the time of cohort entry (e.g. when first identified with dementia on an aged care assessment) indicates that individuals were 84.1 years old on average , and 63.1% were female. More than 44% were first identified at entry to permanent

residential aged care. The cohort recorded more severe cognitive impairment at entry than other international dementia registries.

Findings to date

The cohort has so far been used to demonstrate a declining prevalence of dementia in individuals entering the aged care sector, examine trends in psychotropic medicine prescribing, and to examine the impact of dementia on aged care service use and outcomes.

Future plans

The ROSA dementia cohort will be updated periodically and is a powerful resource both on its own and as a contributor to the Australian dementia CQR. Integration of the ROSA dementia cohort with the dementia CQR will ensure that people with dementia using aged care services can benefit from the ongoing monitoring and benchmarking of care that a registry can provide.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The ROSA dementia cohort includes large cohort of people with dementia from all Australian states and territories, with a wide breadth of linked data to allow for monitoring of care.
- The ROSA dementia cohort does not include people who do not have a diagnosis of dementia or those who have not used government-subsidised aged care services.
- Entry to the ROSA dementia cohort occurs at identification on aged care eligibility assessments, which can be sometime after dementia symptom onset or formal diagnosis. This limits the potential for monitoring early clinical care.

INTRODUCTION

Registries are powerful tools for research and monitoring of clinical care because they facilitate population-level surveillance over time [1,2]. As the global prevalence of dementia rises [3], dementia-related registries are being established internationally to complement clinical research and improve the quality of care for people with this condition [4]. Methods of capturing cases of dementia vary between registries but usually include reporting from specialist clinics and hospitals. Importantly for a dementia registry, diagnosis occurs in a variety of settings and therefore capturing the whole population can be challenging [4].

Dementia is a common chronic health condition in Australia, affecting an estimated one in 10 people aged over 65 years [5]. More than 400,000 people are estimated to be living with dementia in Australia, 25,000 of whom are aged under 65 years [5]. The Australian Dementia Network (ADNeT) Clinical Quality Registry (CQR) is a new national dementia CQR established to monitor, benchmark, and report on the quality of care for people with mild cognitive impairment (MCI) and dementia over time [6]. The ADNeT Registry enrols participants at the point of diagnosis in memory or private specialist clinics and will track longitudinal outcomes via patient and carer reported outcome measures as well as linkage with administrative datasets.

However, many people with dementia or MCI may be diagnosed in other settings [7]. Given the high prevalence of dementia among those accessing government-subsidised aged care services [8], existing aged care assessment data has great potential to contribute to the capture of individuals into the ADNeT CQR. Approximately 47% of Australian residential care users and 21% of home care users have a recorded diagnosis of dementia [8]. It is estimated that aged care assessments conducted from 2009 to 2015 captured approximately 36% of the estimated total population of people with dementia in Australia (prevalent cases) at the end of 2015 [9]. Therefore, understanding and studying the cohort with dementia captured within the aged care sector can significantly contribute to our understanding of the individuals that may not be captured earlier for a national CQR. Information about health service use, medicines, hospitalisations, mortality and other information can then be monitored for these individuals over time.

In our current evaluation we have examined (a) the demographic and clinical features of people with dementia using Australian aged care services and the extent to which these are representative of the broader population of people with dementia in Australia, and (b) the comparability of data captured in aged care datasets to selected established international dementia registries. This will allow for better understanding of the characteristics and

limitations of this cohort for monitoring the quality of care and outcomes for people living with dementia in Australia.

COHORT DESCRIPTION

Design and data sources

A national cohort of all non-Indigenous Australians aged 65 and over who have accessed government-subsidised aged care services from 1997 to 2017 (and updated regularly) is captured in the Registry of Senior Australians (ROSA). In ROSA, national aged care assessment data are linked with information about aged care service use, health service use, medication dispensing, hospitalisations, and death records [10] of individuals that entered the aged care sector. Specifically, assessments within the aged care sector are conducted to determine eligibility for government-subsidised services (by Aged Care Assessment Teams, established in 2003; ACAT) or to identify funding requirements in residential aged care (Aged Care Funding Instrument, established in 2008; ACFI). In both assessments assessors are clinically-trained medical, nursing or allied health professionals who identify the level of care need based on functional and cognitive limitations [11,12]. Data from assessments, as well as aged care service use, are provided to ROSA from the Australian Institute of Health and Welfare National Aged Care Data Clearinghouse.

These data are subsequently linked with information about government-subsidised health service use from the Medicare Benefits Schedule (MBS), medicine dispensing from the Pharmaceutical Benefits Scheme (PBS), state-based hospital records and mortality data from the National Death Index (NDI). The ROSA established this cross-sector data linkage for research purposes and aims to assess the effectiveness, appropriateness, and quality of aged care services provided to older individuals over time. In its entirety, the historical ROSA cohort includes over 2.8 million individuals, including 1.2 million who have had aged care eligibility assessments for substantial aged care services like permanent residential care, home care packages, residential respite care and transition care.

Ethical approval for ROSA was provided by the University of South Australia (reference ID200489), Australian Institute of Health and Welfare (reference EO2018/1/418), South Australian Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South Wales Population and Health Services (reference 2019/ETH12028) Human Research Ethics Committees.

Here we present results of a cross-sectional evaluation of the people with dementia identified in aged care assessment data (hereafter referred to as the 'ROSA dementia cohort') between July 1 2008 and June 30 2016. The entry point to the ROSA dementia cohort is the first aged care assessment where a recording of dementia was made, though the person may have

entered the ROSA with an earlier assessment (on which a dementia diagnosis was not recorded). Entry is distinct from the date of diagnosis, which will have occurred earlier and is not known for our cohort. Where a person is identified from medication prescribing records, data from the closest aged care assessment is included here for cohort profiling.

Dementia ascertainment

Dementia is determined from aged care eligibility assessments (conducted by ACAT), assessments for funding in permanent residential care (conducted using the ACFI), and from pharmaceutical data as captured in PBS. In assessments, assessors record up to 10 (ACAT) or up to three (ACFI) major diseases or disorders that have an impact on the person's need for assistance with activities of daily living and social participation, together with documented evidence of a diagnosis from a medical practitioner. Assessors can record one or more types of dementia or have the option to classify the dementia as 'unspecified' based on the medical record. In addition, medicines prescribed for the treatment of Alzheimer's disease are not dispensed for any other reason. Any person with who has been dispensed donepezil (Anatomical Therapeutic Chemical Classification System code, ATC N06DA02), galantamine (ATC code N06DA04), rivastigmine (ATC code N06DA03) or memantine (ATC code N06DX01) can be classified as having dementia.

Minimum data set

The data available for the ROSA dementia cohort is presented in Table 1, with comparable data from other established dementia registries. Registries included for comparison were chosen based on their broad coverage and the availability of data for comparison here. They include one clinical quality registry (the Swedish Dementia Registry (SveDem)), and two epidemiological dementia registries (French National Alzheimer Database (BNA); Registry of Dementia of Girona, Spain (ReDeGi)).

Table 1. Comparison of the ROSA Dementia Cohort and International Dementia Registries, Minimum Dataset Available

	ROSA Dementia Cohort	Swedish Dementia Registry [13]	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14]	Registry of Dementia for Girona [15]
Country	Australia	Sweden	France	Spain [a]
Demographics	Date of birth Sex Living arrangements Country of birth Language Region Marital status Socioeconomic status [b] Carer availability Carer relationship Carer co-residency (y/n)	Age Sex Living arrangements Driver's licence (y/n) Weapons licence (y/n)	Date of birth Sex Living arrangements Area of birth Education	Date of birth Sex Living arrangement Nationality Region Occupation Education Marital status
Clinical characteristics	Type of dementia	Type of dementia Family history of dementia BMI Total number of diagnostic tests	Type of dementia Procedure type [c]	Type of dementia Family history of dementia Aged at symptom onset (estimated) Date of diagnosis

		Time needed for diagnosis Recommended diagnostic workup (y/n)		
Cognitive testing	PAS-CIS score [d]	MMSE score	MMSE score	MMSE score BDRS score CDRS score
Care use	All government funded aged care (inc. dates and priority) including: • Respite care • Home care • PRAC • Transition care • Other home and community support services Health service use [e]	Respite care (y/n) Home care (y/n) PRAC (date of moving, type of home) [a]	Date of entry to residential care Psychosocial intervention (yes/no)	NA
Medications	All (including dosage and dates) [f]	Anti-dementia (y/n) Antidepressants (y/n) Antipsychotics (y/n) Anxiolytics (y/n) Hypnotics (y/n)	Anti-dementia (y/n) Antidepressants (y/n) Antipsychotics (y/n) Anxiolytics (y/n) Hypnotics (y/n)	Anti-dementia (y/n) Antidepressants (y/n) Antipsychotics (y/n)

		Cardiovascular drugs (y/n) Total number of drugs	Serious drug-related adverse event (y/n)	
Health and wellbeing	Comorbidities [g] Cornell Scale for Depression in Dementia [d]	QUALID [d] Falls, ulcers, malnutrition, oral health (screening and intervention) [d] Links to other registries		Present hypertension, diabetes mellitus, dislipidemia, stroke, thyroid disease History of depression
Function	Activity limitations	IADL score [a]	IADL score	
Death	Date of death Causes of death	Time to death (months)	Date of death	NA

BDRS=Blessed Dementia Rating Scale ; BMI=Body mass index; CDRS=Clinical Dementia Rating Scale; IADL=Instrumental Activities of Daily Living [16]; MMSE=Mini-mental Status Examination [17]; NA=Not available;; PAS-CIS=Psychogeriatric Assessment Scale-Cognitive Impairment Scale; PRAC=Permanent residential aged care; QUALID=Quality of Life in Late-Stage Dementia scale [18]; SD=Standard deviation.

[a] Regional only - Girona

[b] Measured using the Index of Relative Socio-economic Disadvantage compiled by the Australian Bureau of Statistics

[c] Consultation, neuropsychological assessment, day-hospital visit, or group session

[d] PRAC only

[e] Government-subsidised health care services only (i.e. not privately funded), including hospitalisation, emergency department, and ambulance service records for some states.

[f] Government-subsidised medicines only

[g] 204 possible comorbidities recorded by assessors or 46 captured from a medication-based co-morbidity measure

ROSA includes comprehensive demographic data and information about aged and health care service use, including service entry and exit dates. All prescription-based medicine dispensing is recorded by the PBS, facilitating monitoring of medicine dosage, duration, and polypharmacy. Information about family history of dementia, diagnostic procedures, or other clinical details (aside from comorbidities) is not available. ROSA also does not include privately-funded health service use.

Assessments conducted for financial purposes at entry into residential aged care are repeated when care needs change. These include a standardised neuropsychological assessment. While most dementia registries include the Mini-Mental Status Examination (MMSE), copyright restrictions have precluded its widespread clinical use in Australia. Instead, the Psychogeriatric Assessment Scale-Cognitive Impairment Scale (PAS-CIS) [19] is conducted where cognitive impairment is suspected or known. The PAS-CIS correlates strongly with the MMSE [20]. A Cornell Scale for Depression (CSD) [21] is conducted where symptoms of depression and dysthymia are present. Functional dependence is rated across domains (including nutrition, mobility, personal hygiene, toileting, continence, home maintenance, and transport) though a validated measure like those used in other registries is not included.

Cohort characteristics

There were 363,695 people in the ROSA dementia cohort over the capture period (Table 2). Detailed demographic data on the cohort appears in Supplementary Table 1. The cohort is representative of the geographical spread of the Australian population with the majority living in New South Wales, Victoria, and Queensland (76.2%, compared to 77.4% of the general population). Similarly, 33.4% of the ROSA dementia cohort live outside a major city (compared to 28.2% of the general population), 32.9% were born outside Australia (compared to 33.3% of the general population), and 11.5% primarily speak a language other than English (compared to 22.2% of general population households where a non-English language is spoken) [22]. While comparable on sex, the ROSA dementia cohort is older at entry than other registries and includes more people living in permanent residential care.

Table 2. Comparison of the ROSA Dementia Cohort and International Dementia Registries, Demographic Characteristics

	ROSA Dementia Cohort *n*=373,695	Swedish Dementia Registry [13] *n*=28,722 [a]	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14,23] *n*=193,729 [b]	Registry of Dementia for Girona [15] *n*=377
Age at cohort entry (x̄, SD)	84.1 (6.9)	79.3 (8.0)	AD: 81.9 (NA) Other: 79.3 (NA) MCI: 75.1 (NA)	78.9 (7.8)
65-69 years	11,181 (3.0)	NA	NA	NA
70-79 years	78,409 (21.0)	NA	NA	NA
80-89 years	202,519 (54.2)	NA	NA	NA
90+ years	81,586 (21.8)	NA	NA	NA
Sex				
Female	235,703 (63.1)	16,994 (59.2)	123,138 (63.6)	361 (62.6)
Male	137,943 (36.9)	11,728 (40.8)	70,591 (36.4)	216 (37.4)
Missing	49 (0.1)	NA	NA	NA
Living arrangements at entry			(*n*=341,498) [b]	
Lives alone	72,392 (19.4)	25,492 (88.8) [c]	32,034 (9.4)	505 (87.6) [c]
Lives with family or others	134,943 (36.1)		240,967 (70.5)	
PRAC or other	166,349 (44.5)	3230 (10.2)	68,497 (20.1)	72 (12.5)

Timeframes: ROSA July 2008-May 2016; SveDem 2007-2012; BNA 2010-2012; ReDeGi 2007

AD=Alzheimer's disease; ROSA=Registry of Senior Australians; SD=Standard deviation.

[a] Figures published in 2015; the registry included 81,152 individuals in October 2018 (www.ucr.uu.se/svedem/)

[b] Includes 147,769 people with other diagnoses (psychiatric disorders, subjective memory complaints, other neurological disorders, diagnoses pending)

[c] Living in community

Alzheimer's disease (AD) is the most common type of dementia in ROSA, similarly to other registries examined (Table 3). On cognitive assessment, which are only completed by those living in permanent residential care (82% of the cohort had a PAS-CIS score available), the ROSA cohort were more cognitively impaired than the cohorts of other registries.

200 Table 3. Comparison of the ROSA Dementia Cohort and international dementia registries on clinical characteristics

	ROSA Dementia Cohort *n*=309,958 [a]	Swedish Dementia Registry [13] *n*=28,722	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14,23] *n*=193,729	Registry of Dementia for Girona [15] *n*=577
Dementia type				
Alzheimer's disease	229,104 (73.9)	9248 (32.2)	90,176 (46.5)	346 (60.0)
Vascular dementia	33,638 (10.9)	5199 (18.1)		27 (4.7)
Dementia in other diseases	12,271 (4.0)	NA		40 (6.9)
Mixed type	5310 (1.7)	5400 (18.8)	73,982 (38.2) [b]	62 (10.7)
Other dementias (including unspecified)	27,621 (8.9)	8875 (31.1)		102 (17.7)
Mild cognitive impairment	NA	NA	29,571 (15.3)	NA
Missing	2374 (0.8)	NA	NA [c]	0 (0.0)
Cognitive impairment score mean (SD)	PAS-CIS [d] 12.0 (5.1)	MMSE 21.1 (5.1)	MMSE AD: 16.4 Other: 18.5 MCI: 25.6	MMSE 16.8 (5.4)
Cognitive impairment Category	PAS-CIS	MMSE	MMSE	CDR®
No or minimal impairment	7614 (3.6)	NA	21,530 (11.1)	NA
Mild impairment	60,347 (28.4)	NA (32.4)	62,371 (32.2)	350 (60.7)
Moderate impairment	86,742 (40.9)	NA (36.3)	67,716 (35.0)	153 (26.5)
Severe impairment	57,453 (27.1)	NA	17,402 (9.0)	53 (9.2)
Missing	0 (0.0)	NA	24,710 (12.8)	21 (3.6)

AD=Alzheimer's disease; CDRS=Clinical Dementia Rating Scale; MCI=Mild cognitive impairment; MMSE=Mini-mental Status Examination [17]; NA=Not available; PAS-CIS=Psychogeriatric Assessment Scales-Cognitive Impairment Scale; ROSA=Registry of Senior Australians; SD=Standard deviation.

[a] From residential care funding assessments (*n*=63,737 without these assessment data not included)

[b] Vascular dementia, dementia in other disease, mixed type, other dementias, unspecified dementia

[c] 'Diagnosis pending' *n*=69,355

[d] *n*=212,156; PAS-CIS at times not conducted due to severe cognitive impairment, speech impairments, language differences, sensory impairments, or refusal

People in the ROSA dementia cohort have a median four (interquartile range=2) other comorbid health conditions. In SveDem, people with dementia recorded a median Charlson comorbid index score of 2 (IQR=2) [24]. In the ROSA dementia cohort, the most common comorbid conditions were arthritis (35.0%), hypertension (34.9%), and heart diseases (31.7%%). Cerebrovascular disease (15.5%) and hypercholesterolemia (9.1%) were common. Prevalence of hypertension and hypercholesterolemia were lower than the Spanish ReDeGi registry (50.6% and 25.1%, respectively). Prevalence of cerebrovascular disease in our cohort was similar to ReDeGi [15]. In our cohort, more than 99% of individuals reported at least one activity limitation, most often transport (94.7%), health care tasks (92.7%) and social and community participation (92.5%). Individuals in the ROSA dementia cohort lived for an average of two years after they were first identified with dementia in the aged care assessment data and were on average 88 years old (SD=6.6 years) at the time of their deaths. In contrast, a recent analysis of the SveDem cohort identified that only 28% of the cohort had died within the median 2-year follow up period [25]. In ROSA, dementia was recorded as the primary cause of death for 27% of the cohort, most commonly unspecified dementia (15.2%). Other common causes of death were heart diseases (21.8%) and cerebrovascular disease (21.1%).

Patient and Public Involvement

Consumer representatives are part of the governance structure of ROSA and provided oversight for ROSA's development and now oversee ongoing operations.

FINDINGS TO DATE

To date, the ROSA dementia cohort has been used to demonstrate a declining prevalence of dementia in individuals entering the aged care sector [8], to determine that there is a higher prescribing of psychotropic medicines in people with dementia in residential care, to show the value of residential respite for delaying institutionalisation for people with dementia [26], and to highlight poorer outcomes after hip fracture among those with pre-morbid dementia than without dementia [27]. The broader ROSA dataset has also recently been used to develop an Outcome Monitoring System for aged care, with 12 indicators of care quality that can be monitored over time and across geographical areas [28]. Most of these indicators are relevant to dementia care, including psychotropic medicine use, hospitalisations, and falls, and work is underway to apply them to the monitoring of care in the ROSA dementia cohort.

STRENGTHS AND LIMITATIONS

The large sample and national coverage provided by ROSA are key strengths of the ROSA dementia cohort. ROSA includes the largest existing population-based sample of people with dementia in Australia and is representative of the population in many ways, including sex,

regionality, and cultural and linguistic diversity. An average of 37,661 new cases of dementia are identified in ROSA each year and many of these may not be identified via other sources [9]. The ROSA dementia cohort is therefore a powerful resource both on its own and as a contributor to the ADNeT CQR [6]. A wide breadth of data is available in ROSA and this is expanding as linkage to new state-based data sources continues, including hospitalisations and ambulance use. These data can facilitate monitoring of clinical care and determinants of important outcomes including institutionalisation and mortality over time.

Despite these benefits, there are important limitations to the ROSA dementia cohort. First, we cannot capture people with dementia who do not have a diagnosis, nor those who do not access aged care services. Approximately half of people with dementia in Australia are estimated to receive a diagnosis [7,29,30], and delays in diagnosis are common [7,31]. People who do receive a diagnosis tend to have more severe impairment, have insight into their impairment, speak English, live in metropolitan areas and in areas with greater access to health services, have higher levels of education, and be married [32]. Also, one in three women and one in two men will not use an aged care service in their lifetime [33]; ROSA is not able to capture these individuals and these factors introduce a sampling bias to our cohort.

Second, two important groups are not represented in the current ROSA cohort. People who accessed aged care services before 65 years of age but died before turning 65 years old are

not included. We estimate that ROSA currently captures 40-84% of those aged under 65 using aged care (depending on the year). The number of missing cases of dementia attributable to this data gap is likely to be small given that most people with symptom onset prior to 65 years are aged 60-64 years at onset and will age over 65 years with their condition [34]. Nonetheless, types of dementia that are most common in younger groups (for example alcohol-related dementias, frontotemporal dementias, dementia in Huntington's disease, dementia in Down syndrome) are likely to be underrepresented. ROSA also does not currently include Aboriginal and Torres Strait Islander people, though consultation is under way to enable inclusion of this cohort in future analyses.

Third, the data available in ROSA is not collected for research purposes and therefore may have limited internal validity. While the 'breadth' of data is a key strength of this cohort, its relative lack of 'depth' is a limitation and the suitability of service use is difficult to assess. The accuracy of clinical and demographic data also relies on assessors who are not necessarily trained in research data collection or in dementia care. Aged care assessors are limited to recording a maximum of 10 health conditions (ACAT) or three mental/cognitive conditions (ACFI) per assessment; whether dementia is considered an important enough comorbidity to be listed is at the assessors' discretion. In the absence of cognitive assessment, the accuracy of the dementia diagnosis recorded in ROSA is dependent on the skills and resources

available to the clinician who made the diagnosis. Additionally, ROSA is not a dementia-specific registry and includes fewer clinical details than available in other cohorts.

Finally, aged care eligibility assessments can occur sometime after dementia symptom onset or formal diagnosis, limiting the potential for monitoring early clinical care. More than 36% of individuals entered the ROSA dementia cohort at entry to or while living in residential aged care, which is likely to be late in their disease path. As such, people living in permanent residential care are overrepresented in ROSA compared to national estimates [5] and to other registries that recruit at the time of diagnosis. They are also likely to have more functional limitations and comorbid health conditions and to die sooner than other registries, though little data from other registries is available for comparison. Capture of those entering residential care for a dementia CQR is nonetheless important given that many will not be identified elsewhere.

COLLABORATION

ROSA is the product of a consortium of 13 academic, clinical, industry, consumer representative and public health organisations [10]. The consortium oversees ROSA management and use, ensuring that ROSA projects have clinical and public health relevance. Results described here demonstrate that aged care assessment data can be a valuable

resource for maximising capture for the ADNeT CQR. Linkage between ROSA and ADNeT will ensure both that monitoring of care can occur early in the disease course, and that people with dementia using aged care services can benefit from the ongoing monitoring and benchmarking of their clinical care.

Other collaboration is welcomed, and researchers interested in collaboration are invited to contact the research team to access all data available in ROSA. In addition to the data described here, similar data is available from aged care users without dementia and state-based hospitalisation data for some Australian states. Data linkage is ongoing and is being updated over time, and we particularly encourage collaboration with those with other datasets that could be linked. Data access is subject to ethical and governance approval.

AUTHOR CONTRIBUTIONS

MI, MCr, and SW conceptualised the project, obtained funding, and assisted with reviewing and editing the manuscript. MCa drafted, reviewed, and edited the manuscript. MCa and CL conducted data analysis. CW and JM provided oversight to the project and assisted with manuscript review and editing. All authors read and approved the final manuscript.

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CONFLICTS OF INTEREST

MCa has been employed in the last five years to assist with data collection for drug trials funded by Janssen and Merck. All other authors declare no conflicts of interest.

ETHICAL APPROVAL

Ethical approval was provided by the University of South Australia (reference ID200489), Australian Institute of Health and Welfare (reference EO2018/1/418), South Australian Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South Wales Population and Health Services (reference 2019/ETH12028) Human Research Ethics Committees.

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DATA AVAILABILITY STATEMENT

Researchers interested in collaboration are invited to contact the research team to access the data available in ROSA. In addition to the data described here, similar data is available from aged care users without dementia, and state-based hospitalisation data for some Australian states. Data linkage is ongoing and is being updated over time.

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SUPPLEMENTARY MATERIALS

Supplementary Table 1. The ROSA Dementia Cohort Comprehensive Demographic and Clinical Characteristics

		n (%)
		All (*n*=373,695)
Age at cohort entry (mean, SD)		84.1 (6.9)
	65-69	11,181 (3.0)
	70-79	78,409 (21.0)
	80-89	202,519 (54.2)
	>89	81,586 (21.8)
Sex		
	Female	235,703 (63.1)
	Male	137,943 (36.9)
	Missing	49 (0.1)
Country of birth		
	Australia	348,396 (66.5)
	Outside Australia	123,009 (32.9)
	Missing	2290 (0.6)
Language		
	English	329,108 (88.1)
	Other	42,779 (11.5)
	Missing	1808 (0.5)
State		
	New South Wales	127,830 (34.2)
	Victoria	92,911 (24.9)
	Queensland	63,986 (17.1)
	Western Australia	35,689 (9.6)
	South Australia	34,252 (9.2)
	Tasmania	9379 (2.5)
	Northern Territory	780 (0.2)
	Australian Capital Territory	4114 (1.10)
	Missing	4754 (1.3)
ARIA Region [a]		
	Major city	245,083 (65.6)
	Inner regional	78,320 (21.0)
	Outer regional	37,378 (10.0)
	Remote	4074 (1.1)
	Very remote	1307 (0.4)
	Missing	7533 (2.0)
Socio-economic status (derived from postcode using IRSD)		
	Most Disadvantaged -1	61,573 (16.5)
	2	63,830 (17.1)
	3	65,613 (17.6)
	4	70,050 (18.8)
	Least Disadvantaged- 5	105,029 (18.8)
	Missing	7600 (2.0)
Marital status		
	Married	133,647 (35.8)
	Separated or divorced	23,727 (6.3)
	Widowed	176,949 (47.4)
	Never married	17,950 (4.8)
	Missing	21,412 (5.7)
Carer availability [b] (*n*=214,780)		
	Has carer	185,118 (86.2)
	No carer	14,781 (6.9)
	Missing	14,836 (6.9)

	n (%)
	All (*n*=373,695)
Carer relationship [b] (*n*=185,118)	
Spouse	80,094 (43.3)
Parent	164 (0.9)
Child or child-in-law	88,105 (47.6)
Other relative	10,075 (5.4)
Friend/neighbour	5967 (3.2)
Missing	676 (0.4)
Carer co-residency [b] (*n*=185,118)	117,617 (63.5)
Dementia identified	
Medicine dispensing only	3694 (1.0)
ACAP or medicine dispensing only	62,417 (16.7)
ACFI or medicine dispensing only	161,135 (43.1)
Both ACAP and ACFI	146,449 (39.2)
Dementia first identified using [c]	
ACAP	207,346 (55.5)
ACFI	166,349 (44.5)
Number Medical Conditions (median, IQR) [f]	4 (4-6)
0	11,862 (3.2)
1-4	170,826 (45.7)
5-9	151,358 (40.5)
10+	13,747 (3.7)
Missing	25,875 (6.9)
Activity limitations [b] (*n*=214,780)	
None	405 (0.2)
Communication	66,745 (31.1)
Domestic assistance	190,642 (88.8)
Health care tasks	199,163 (92.7)
Home maintenance	161,220 (75.1)
Meals	186,390 (86.8)
Movement activities	60,528 (28.2)
Moving around places	139,482 (64.9)
Self-care	164,446 (76.6)
Transport	203,395 (94.7)
Social and community participation	198,743 (92.5)
Other	12,478 (5.8)
Most common co-morbidities at cohort entry	
Arthritis (rheumatoid and other)	130,824 (35.0)
Hypertension	130,569 (34.9)
Heart diseases	118,274 (31.7)
Falls	58,136 (15.6)
Cerebrovascular disease	57,772 (15.5)
Osteoporosis	54,555 (14.6)
Diabetes – type 2	54,026 (14.5)
Abnormalities of gait and mobility	48,151 (12.9)
Deafness/hearing loss	41,480 (11.1)
Hypercholesterolemia	14,043 (9.1)
Cornell Scale for Depression [g] (*n*=122,253) (mean, SD)	11.7 (6.7)
Dead at June 30 2016	249.682 (66.8)
Age at death (*n*=249,682) (mean, SD)	87.5 (6.6)
Years from cohort entry to death (*n*=249,682) (mean, SD)	2.1 (1.7)
Primary cause of death (*n*=249,682)	
Circulatory disease	87,604 (35.1)
Heart disease	54,412 (21.8)
Cerebrovascular disease	30,246 (21.1)

	n (%)
	All (*n*=373,695)
Dementias	66,287 (26.5)
Unspecified dementia	38,019 (15.2)
Alzheimer's disease	21,090 (8.4)
Vascular dementia	7178 (2.9)
Respiratory disease (including pneumonia)	19,675 (7.9)
Other causes	76,116 (30.5)

ACAP=Aged Care Assessment Program; ACFI=Aged Care Funding Instrument; ARIA=Accessibility/Remoteness Index of Australia; IQR=Interquartile range; IRSD=Index of Relative Socio-Economic Disadvantage; SD=Standard deviation

[a] Remoteness categories are from the Accessibility/Remoteness Index of Australia Plus (ARIA+) 2016. These have also been linked to the cohort based on the postcode at the time of the assessment.

[b] From ACAP recordings – includes ACAP data for *n*=7,434 individuals who entered the ROSA dementia cohort from an earlier ACFI assessment.

[c] Or medicine dispensing closest to one of these

[d] From July 2008

[e] To June 2016

[f] From RxRisk, medicine-based comorbidity measure

[g] From ACFI recordings – includes ACFI data (at entry to permanent residential aged care) for some individuals who entered the ROSA dementia cohort from an earlier ACAT assessment