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Cohort profile: Dementia in the Registry of Senior Australians

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3 1 **TITLE**
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3 20 **ABSTRACT**
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7 21 **Purpose**
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11 22 Clinical quality registries (CQR) are being established in many countries to monitor,
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14 23 benchmark, and report on the quality of dementia care over time. Case ascertainment can be
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17 24 challenging given that diagnosis occurs in a variety of settings. The Registry of Senior
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20 25 Australians (ROSA) includes a large cohort of people with dementia from all Australian states
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23 26 and territories identified using routinely-collected aged care assessment data. In ROSA,
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26 27 assessment data is linked to information about aged and health service use, medicine
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29 28 dispensing, hospitalisations, and the National Death Index. The ROSA dementia cohort was
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32 29 established to capture people for the Australian dementia CQR currently in development who
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35 30 may not be identified elsewhere.
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41 31 **Participants**
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45 32 There were 313,544 people with dementia identified in aged care assessments from 2008 to
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48 33 2016. Individuals were 83.6 years old on average at cohort entry (e.g. when first identified with
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51 34 dementia on an aged care assessment), and 60.6% were female. More than 36% were first
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54 35 identified at entry to permanent residential aged care. The cohort recorded more severe
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57 36 cognitive impairment than other international dementia registries.
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3 **37 Findings to date**
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7 **38** The cohort has so far been used to demonstrate a declining prevalence of dementia in
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10 **39** individuals entering the aged care sector, examine trends in psychotropic medicine
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14 **40** prescribing, and to examine the impact of dementia on aged care service use and outcomes.
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18 **41 Future plans**
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22 **42** The ROSA dementia cohort will be updated periodically and is a powerful resource both on its
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25 **43** own and as a contributor to the Australian dementia CQR. Integration of the ROSA dementia
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28 **44** cohort with the dementia CQR will ensure that people with dementia using aged care services
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31 **45** can benefit from the ongoing monitoring and benchmarking of care that a registry can provide.
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46 STRENGTHS AND LIMITATIONS OF THIS STUDY

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

55 INTRODUCTION

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

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

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4 72 However, many people with dementia or MCI may be diagnosed in other settings [7]. Given
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7 73 the high prevalence of dementia among those accessing government-subsidised aged care
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10 74 services [8], existing aged care assessment data has great potential to contribute to the
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13 75 capture of individuals into the ADNeT CQR. Approximately 47% of Australian residential care
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16 76 users and 21% of home care users have a recorded diagnosis of dementia [8]. It is estimated
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19 77 that aged care assessments conducted from 2009 to 2015 captured approximately 36% of the
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22 78 estimated total population of people with dementia in Australia (prevalent cases) at the end of
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26 79 2015 (unpublished data). Therefore, understanding and studying the cohort of individuals with
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29 80 dementia captured within the aged care sector can significantly contribute to our
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32 81 understanding of the individuals that may not be captured earlier for a national CQR.
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35 82 Information about health service use, medicines, hospitalisations, mortality and other
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38 83 information can then be monitored for these individuals over time.
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42 84 In our current evaluation we have examined (a) the demographic and clinical features of
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46 85 people with dementia using Australian aged care services and the extent to which these are
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49 86 representative of the broader population of people with dementia in Australia, and (b) the
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52 87 comparability of data captured in aged care datasets to selected established international
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55 88 dementia registries. This will allow for better understanding of the characteristics and
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3 89 limitations of this cohort for monitoring the quality of care and outcomes for people living with
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11 91 **COHORT DESCRIPTION**
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15 92 **Design and data sources**
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19 93 A national cohort of all non-Indigenous Australians aged 65 and over who have accessed
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22 94 government-subsidised aged care services from 1997 to 2017 (and updated regularly) is
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25 95 captured in the Registry of Senior Australians (ROSA). In ROSA, national aged care
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28 96 assessment data are linked with information about aged care service use, health service use,
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31 97 medication dispensing, hospitalisations, and death records [9] of individuals that entered the
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34 98 aged care sector. Specifically, assessments within the aged care sector are conducted to
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37 99 determine eligibility for government-subsidised services (by Aged Care Assessment Teams,
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41 100 established in 2003; ACAT) or to identify funding requirements in residential aged care (Aged
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44 101 Care Funding Instrument, established in 2008; ACFI). In both assessments assessors are
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47 102 clinically-trained medical, nursing or allied health professionals who identify the level of care
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50 103 need based on functional and cognitive limitations [10,11]. Data from assessments, as well as
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54 104 aged care service use, are provided to ROSA from the Australian Institute of Health and
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57 105 Welfare National Aged Care Data Clearinghouse.
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4 106 These data are subsequently linked with information about government-subsidised health
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7 107 service use from the Medicare Benefits Schedule (MBS), medicine dispensing from the
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10 108 Pharmaceutical Benefits Scheme (PBS), state based hospital records (for South Australia,
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13 109 New South Wales, and Victoria) and mortality data from the National Death Index (NDI). The
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16 110 ROSA established this cross-sector data linkage for research purposes and aims to assess
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19 111 the effectiveness, appropriateness, and quality of aged care services provided to older
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22 112 individuals over time. In its entirety, the historical ROSA cohort includes over 2.8 million
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26 113 individuals, including 1.2 million who have had aged care eligibility assessments for substantial
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29 114 aged care services like permanent residential care, home care packages, residential respite
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32 115 care and transition care.

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36 116 Ethical approval for ROSA was provided by the University of South Australia (reference
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39 117 ID200489), Australian Institute of Health and Welfare (reference EO2018/1/418), South
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42 118 Australian Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South
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46 119 Wales Population and Health Services (reference 2019/ETH12028) Human Research Ethics
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49 120 Committees.

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53 121 Here we present results of a cross-sectional evaluation of the people with dementia identified
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56 122 in aged care assessment data (hereafter referred to as the 'ROSA dementia cohort') between
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59 123 July 1 2008 and May 31 2016. The entry point to the ROSA dementia cohort is the first aged

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4 124 care assessment where a recording of dementia was made, though the person may have
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7 125 entered the ROSA with an earlier assessment (on which a dementia diagnosis was not
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10 126 recorded). Entry is distinct from the date of diagnosis, which will have occurred earlier. Where
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13 127 a person is identified from medication prescribing records, data from the closest aged care
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16 128 assessment is included here for cohort profiling.

19 20 129 **Dementia ascertainment**

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24 130 Dementia is determined from aged care eligibility assessments (conducted by Aged Care
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27 131 Assessment Teams; ACAT), assessments for funding in permanent residential care
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30 132 (conducted using the Aged Care Funding Instrument; ACFI), and from pharmaceutical data
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34 133 as captured in the Pharmaceutical Benefits Scheme (PBS) In assessments, assessors record
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37 134 up to 10 (ACAT) or up to three (ACFI) major diseases or disorders that have an impact on the
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40 135 person's need for assistance with activities of daily living and social participation, together with
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43 136 documented evidence of a diagnosis from a medical practitioner. Assessors can record one
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47 137 or more types of dementia or have the option to classify the dementia as 'unspecified' based
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50 138 on the medical record. In addition, medicines prescribed for the treatment of Alzheimer's
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53 139 disease are not dispensed for any other reason. Any person with who has been dispensed
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56 140 donepezil (Anatomical Therapeutic Chemical Classification System code, ATC N06DA02),
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4 141 galantamine (ATC code N06DA04), rivastigmine (ATC code N06DA03) or memantine (ATC
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7 142 code N06DX01) can be classified as having dementia.
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11 143 **Minimum data set**
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15 144 The data available for the ROSA dementia cohort is presented in Table 1, with comparable
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18 145 data from other established dementia registries. Registries included for comparison were
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21 146 chosen based on their broad coverage and the availability of data for comparison here. They
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24 147 include one clinical quality registry (the Swedish Dementia Registry (SveDem)), two
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27 148 epidemiological dementia registries (French National Alzheimer Database (BNA); Registry of
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30 149 Dementia of Girona, Spain (ReDeGi)) and one dementia research registry (United States
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34 150 National Alzheimer's Coordinating Centre Unified Dataset (NACC-UDS)).
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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	Age	Date of birth	Date of birth	Date of birth
	Sex	Sex	Sex	Sex	Sex
	Living arrangements	Living arrangements	Living arrangements	Living arrangement	Living arrangements
	Country of birth	Driver's licence (y/n)	Area of birth	Nationality	Ethnicity
	Language	Weapons licence (y/n)	Education	Region	Language
	Region			Occupation	Education
	Marital status			Education	Marital status
	Socioeconomic status			Marital status	Handedness
	^b				Carer demographics
	Carer availability				
	Carer relationship				
	Carer co-residency (y/n)				
Clinical characteristics	Type of dementia	Type of dementia	Type of dementia	Type of dementia	Type of dementia
		Family history of dementia	Procedure type ^c	Family history of dementia	Family history of dementia
		BMI		Aged at symptom onset (estimated)	Age at dementia symptom onset
		Total number of diagnostic tests		Date of diagnosis	Smoking status/volume
					Alcohol use

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		Time needed for diagnosis			BMI
		Recommended diagnostic workup (y/n)			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: <ul style="list-style-type: none"> • 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)	Anxiolytics (y/n)		
		Hypnotics (y/n)	Hypnotics (y/n)		
		Cardiovascular drugs (y/n)	Serious drug-related adverse event (y/n)		
		Total number of drugs			
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

152 BDRS=Blessed Dementia Rating Scale ; BMI=Body mass index; CDRS=Clinical Dementia Rating Scale; IADL=Instrumental Activities of Daily Living [16];

153 MMSE=Mini-mental Status Examination [17]; NA=Not available; NPI=Neuropsychiatric Inventory; PAS-CIS=Psychogeriatric Assessment Scale-Cognitive

154 Impairment Scale; PRAC=Permanent residential aged care; QUALID=Quality of Life in Late-Stage Dementia scale [18]; SD=Standard deviation; USA=United

155 States of America.

156 ^a Regional only - Girona

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

158 ^c Consultation, neuropsychological assessment, day-hospital visit, or group session

159 ^d PRAC only

160 ^e Version 1,2 (until March 2015)

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3 161 ^f Version 3 (from March 2015)
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5 162 ^g Includes Logical Memory IA (Immediate) and IIA (Delayed), Digit Span Forward, Digit Span Backward, Category Fluency, Trail Making Test, Digit Symbol,
6 163 Boston Naming Test
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8 164 ^h Government-subsidised health care services only (i.e. not privately funded), including hospitalisation, emergency department, and ambulance service records
9 165 for some states.
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11 166 ⁱ Government-subsidised medicines only
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13 167 ^j 204 possible comorbidities recorded by assessors or 46 captured from a medication-based co-morbidity measure
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3 168 ROSA includes comprehensive demographic data and information about aged and health care
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6 169 service use, including service entry and exit dates. All prescription-based medicine dispensing
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9 170 is recorded by the PBS, facilitating monitoring of medicine dosage, duration, and
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12 171 polypharmacy. Information about family history of dementia, diagnostic procedures, or other
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15 172 clinical details (aside from comorbidities) is not available. ROSA also does not include
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18 173 privately-funded health service use.
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23 174 Assessments conducted for financial purposes at entry into residential aged care are repeated
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26 175 when care needs change. These include a standardised neuropsychological assessment.
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30 176 While most dementia registries include the Mini-Mental Status Examination (MMSE), copyright
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33 177 restrictions have precluded its widespread clinical use in Australia. Instead, the
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36 178 Psychogeriatric Assessment Scale-Cognitive Impairment Scale (PAS-CIS) [19] is conducted
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39 179 where cognitive impairment is suspected or known. The PAS-CIS correlates strongly with the
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42 180 MMSE [20]. A Cornell Scale for Depression (CSD) [21] is conducted where symptoms of
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45 181 depression and dysthymia are present. Functional dependence is rated across domains
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48 182 (including nutrition, mobility, personal hygiene, toileting, continence, home maintenance, and
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51 183 transport) though a validated measure like those used in other registries is not included.
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56 184 **Cohort characteristics**
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4 185 There were 313,544 people in the ROSA dementia cohort over the capture period (Table 2).
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7 186 Detailed demographic data on the cohort appears in Supplementary Table 1. The cohort is
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10 187 representative of the geographical spread of the Australian population with the majority living
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13 188 in New South Wales, Victoria, and Queensland (76.3%, compared to 77.4% of the general
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16 189 population). Similarly, 33.9% of the ROSA dementia cohort live outside a major city
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19 190 (compared to 28.2% of the general population), 33.6% were born outside Australia (compared
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22 191 to 33.3% of the general population), and 11.5% primarily speak a language other than English
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26 192 (compared to 22.2% of general population households where a non-English language is
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29 193 spoken) [22]. While comparable on sex, the ROSA dementia cohort is older at entry than other
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32 194 registries and includes more people living in permanent residential care.
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195 Table 2. Comparison of the ROSA Dementia Cohort and International Dementia Registries, Demographic Characteristics

	ROSA Dementia Cohort <i>n</i> =313,544	Swedish Dementia Registry [12] <i>n</i> =28,722 ^a	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [13,23] <i>n</i> =193,729 ^b	Registry of Dementia for Girona [14] <i>n</i> =2,777	National Alzheimer's Coordinating Centre Unified Data Set [24] <i>n</i> =25,429
Age at cohort entry (\bar{x} , 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 (6.6)	24,023 (57.2)
Male	123,567 (39.4)	11,728 (40.8)	70,591 (36.4)	216 (3.4)	17,999 (42.8)
Living arrangements at entry			(<i>n</i> =341,498) ^b		
Lives alone	72,422 (23.1)	25,492 (88.8) ^c	32,034 (9.4)	505 (8.6) ^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 (1.5)	NA

196 Timeframes: ROSA July 2008-May 2016; SveDem 2007-2012; BNA 2010-2012; ReDeGi 2007; NACC UDS 2005-2019

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

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3 198 ^a Figures published in 2015; the registry included 81,152 individuals in October 2018 (www.ucr.uu.se/svedem/)
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5 199 ^b Includes 147,769 people with other diagnoses (psychiatric disorders, subjective memory complaints, other neurological
6 200 disorders, diagnoses pending)
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8 201 ^c Living in community
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3 202 Alzheimer's disease (AD) is the most common type of dementia in ROSA, similarly to other
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6 203 registries examined (Table 3). On cognitive assessment, which are only completed by those
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9 204 living in permanent residential care (76% of the cohort had a PAS-CIS score available), the
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13 205 ROSA cohort were more cognitively impaired than the cohorts of other registries.
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Table 3. Comparison of the ROSA Dementia Cohort and international dementia registries on clinical characteristics

	ROSA Dementia Cohort <i>n</i> =243,477 ^a	Swedish Dementia Registry [12] <i>n</i> =28,722	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [13,23] <i>n</i> =193,729	Registry of Dementia for Girona February 2021. Downloaded from http://bmjopen.bmj.com/ on April 23, 2024 by guest. Protected by copyright.	National Alzheimer's Coordinating Centre Unified Data Set <i>n</i> =25,429 [25]
Dementia type					
Alzheimer's disease	177,209 (72.8)	9248 (32.2)	90,176 (46.5)	346 (0.0)	13,424 (52.8)
Vascular dementia	27,493 (11.3)	5199 (18.1)		27 (4.0)	446 (1.8)
Dementia in other diseases	9680 (3.8)	NA		40 (6.0)	
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	MMS 16.8 (4.4)	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 (6.7)	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 (9.0)	NA
Missing	4 (0.0)	NA	24,710 (12.8)	21 (3.0)	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

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4 206 People in the ROSA dementia cohort have a median four (interquartile range=2) other
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7 207 comorbid health conditions. In SveDem, people with dementia recorded a median Charlson
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10 208 comorbid index score of 2 (IQR=2) [26]. In the ROSA dementia cohort, the most common
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13 209 comorbid conditions were hypertension (54.3%), arthritis (51.6%), and heart diseases
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16 210 (48.5%). Cerebrovascular disease (22.1%) and hypercholesterolemia (15.6%) were common.
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19 211 Prevalence of hypertension was similar to both the Spanish ReDeGi (50.6%) and the US
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22 212 NACC UDS (35-87%) registries, while prevalence of hypercholesterolemia was lower than
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25 213 both of these registries (25.1% and 38-78%, respectively). Prevalence of cerebrovascular
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28 214 disease in our cohort was similar to ReDeGi [14]. In our cohort, more than 99% of individuals
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31 215 reported at least one activity limitation, most often transport (94.7%), health care tasks (92.7%)
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34 216 and social and community participation (92.5%). Individuals in the ROSA dementia cohort
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37 217 lived for an average of two years after they were first identified with dementia in the aged care
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40 218 assessment data and were on average 87 years (SD=6.6 years) at the time of their deaths. In
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43 219 contrast, a recent analysis of the SveDem cohort identified that only 28% of the cohort had
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46 220 died within the median 2-year follow up period [27]. In ROSA, dementia was recorded as the
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49 221 primary cause of death for 25% of the cohort, most commonly unspecified dementia (14.4%).
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52 222 Other common causes of death were heart diseases (21.9%) and cerebrovascular disease
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55 223 (11.7%).
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3 224 **FINDINGS TO DATE**
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7 225 To date, the ROSA dementia cohort has been used to demonstrate a declining prevalence of
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10 226 dementia in individuals entering the aged care sector [8], to determine that there is a higher
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13 227 prescribing of psychotropic medicines in people with dementia in residential care, to show the
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17 228 value of residential respite for delaying institutionalisation for people with dementia [28], and
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20 229 to highlight poorer outcomes after hip fracture among those with pre-morbid dementia than
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23 230 without dementia [29].
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27 231 **STRENGTHS AND LIMITATIONS**
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31 232 The large sample and national coverage provided by ROSA are key strengths of the ROSA
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34 233 dementia cohort. ROSA includes the largest existing population-based sample of people with
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38 234 dementia in Australia and is representative of the population in many ways, including sex,
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41 235 regionality, and cultural and linguistic diversity. An average of 37,661 new cases of dementia
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44 236 are identified in ROSA each year and many of these may not be identified via other sources.
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47 237 The ROSA dementia cohort is therefore a powerful resource both on its own and as a
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50 238 contributor to the ADNeT CQR [6]. A wide breadth of data is available in ROSA and this is
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54 239 expanding as linkage to new state-based data sources continues, including hospitalisations
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3 240 and ambulance use. These data can facilitate monitoring of clinical care and determinants of
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6 241 important outcomes including institutionalisation and mortality over time.
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10 242 Despite these benefits, there are important limitations to the ROSA dementia cohort. First, we
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13 243 cannot capture people with dementia who do not have a diagnosis, nor those who do not
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16 244 access aged care services. Approximately half of people with dementia in Australia are
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19 245 estimated to receive a diagnosis [7,30,31], and delays in diagnosis are common [7,32]. People
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22 246 who do receive a diagnosis tend to have more severe impairment, have insight into their
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25 247 impairment, speak English, live in metropolitan areas and in areas with greater access to
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28 248 health services, have higher levels of education, and be married [33]. Also, one in three
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31 249 women and one in two men will not use an aged care service in their lifetime [34]; ROSA is
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34 250 not able to capture these individuals and these factors introduce a sampling bias to our cohort.
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40 251 Second, two important groups are not represented in the current ROSA cohort. People who
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43 252 accessed aged care services before 65 years of age but died before turning 65 years old are
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46 253 not included. We estimate that ROSA currently captures 40-84% of those aged under 65 using
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49 254 aged care (depending on the year). The number of missing cases of dementia attributable to
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52 255 this data gap is likely to be small given that most people with symptom onset prior to 65 years
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55 256 are aged 60-64 years at onset and will age over 65 years with their condition [35]. Nonetheless,
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58 257 types of dementia that are most common in younger groups (for example alcohol-related
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4 258 dementias, frontotemporal dementias, dementia in Huntington's disease, dementia in Down
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7 259 syndrome) are likely to be underrepresented. ROSA also does not currently include Aboriginal
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10 260 and Torres Strait Islander people, though consultation is under way to enable inclusion of this
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13 261 cohort in future analyses.

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17 262 Third, the data available in ROSA is not collected for research purposes and therefore may
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20 263 have limited internal validity. While the 'breadth' of data is a key strength of this cohort, its
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23 264 relative lack of 'depth' is a limitation and the suitability of service use is difficult to assess. The
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26 265 accuracy of clinical and demographic data also relies on assessors who are not necessarily
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29 266 trained in research data collection or in dementia care. Aged care assessors are limited to
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32 267 recording a maximum of 10 health conditions (ACAT) or three mental/cognitive conditions
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35 268 (ACFI) per assessment; whether dementia is considered an important enough comorbidity to
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38 269 be listed is at the assessors' discretion. In the absence of cognitive assessment, the accuracy
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41 270 of the dementia diagnosis recorded in ROSA is dependent on the skills and resources
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44 271 available to the clinician who made the diagnosis. Additionally, ROSA is not a dementia-
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47 272 specific registry and includes fewer clinical details than available in other cohorts.
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53 273 Finally, aged care eligibility assessments can occur sometime after dementia symptom onset
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56 274 or formal diagnosis, limiting the potential for monitoring early clinical care. More than 36% of
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59 275 individuals entered the ROSA dementia cohort at entry to or while living in residential aged

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3 276 care, which is likely to be late in their disease path. As such, people living in permanent
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6 277 residential care are overrepresented in ROSA compared to national estimates [5] and to other
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9 278 registries that recruit at the time of diagnosis. They are also likely to have more functional
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12 279 limitations and comorbid health conditions and to die sooner than other registries, though little
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15 280 data from other registries is available for comparison. Capture of those entering residential
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18 281 care for a dementia CQR is nonetheless important given that many will not be identified
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22 282 elsewhere.

26 283 **COLLABORATION AND PATIENT AND PUBLIC INVOLVEMENT**

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30 284 ROSA is the product of a consortium of 13 academic, clinical, industry, consumer
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33 285 representative and public health organisations [9]. The consortium oversees ROSA
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36 286 management and use, ensuring that ROSA projects have clinical and public health relevance.
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39 287 Consumer representatives are part of the governance structure of ROSA, which provided
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42 288 oversight for ROSA's development and now ongoing operations. Results described here
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45 289 demonstrate that aged care assessment data can be a valuable resource for maximising
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48 290 capture for the ADNeT CQR. The ongoing collaboration between ROSA and ADNeT will
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51 291 ensure that people with dementia using aged care services can benefit from the ongoing
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54 292 monitoring and benchmarking of their clinical care.
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4 293 **AUTHOR CONTRIBUTIONS**

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7 294 MCI, MCr, and SW conceptualised the project, obtained funding, and assisted with reviewing
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9
10 295 and editing the manuscript. MCA drafted, reviewed, and edited the manuscript. MCA and CL
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12
13 296 conducted data analysis. CW and JM provided oversight to the project and assisted with
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16
17 297 manuscript review and editing. All authors read and approved the final manuscript.
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32
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34
35
36 303 design, methods, data collection and analysis, decision to publish or preparation of this
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38
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40 304 manuscript. All authors had final responsibility for the decision to submit for publication.
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44 305 **CONFLICTS OF INTEREST**

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48 306 MCA has been employed in the last five years to assist with data collection for drug trials
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51 307 funded by Janssen and Merck. All other authors declare no conflicts of interest.
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55 308 **ETHICAL APPROVAL**
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4 309 Ethical approval was provided by the University of South Australia (reference ID200489),
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7 310 Australian Institute of Health and Welfare (reference EO2018/1/418), South Australian
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10 311 Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South Wales
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13 312 Population and Health Services (reference 2019/ETH12028) Human Research Ethics
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16 313 Committees.

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SUPPLEMENTARY MATERIALS

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

	<i>n</i> (%)	
	All (<i>n</i> =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 (<i>n</i> =214,794)		
	Has carer	185,144 (86.2)
	No carer	14,785 (6.9)
	Missing	14,865 (6.9)

		<i>n</i> (%)
		All (<i>n</i> =313,544)
Carer relationship ^b (<i>n</i> =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 (<i>n</i> =185,144)		
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		
	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 (<i>n</i> =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 (<i>n</i> =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)

	<i>n</i> (%)
	All (<i>n</i> =313,544)
Cornell Scale for Depression [§] (<i>n</i> =78,400) (mean, SD)	12.2 (6.6)
Dead at May 31 2016	191,721 (61.2)
Age at death (<i>n</i> =191,721) (mean, SD)	87.0 (6.6)
Years from cohort entry to death (<i>n</i> =191,721) (mean, SD)	2.0 (1.7)
Primary cause of death (<i>n</i> =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

[§] From ACFI recordings at cohort entry

BMJ Open

Cohort profile: Dementia in the Registry of Senior Australians

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1 **TITLE**

2 Cohort profile: Dementia in the Registry of Senior Australians

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20 ABSTRACT

21 Purpose

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

31 Participants

32 There were 373,695 people with dementia identified in aged care assessments from 2008 to
33 2016. Individuals were 84.1 years old on average at cohort entry (e.g. when first identified with
34 dementia on an aged care assessment), and 63.1% were female. More than 44% were first
35 identified at entry to permanent residential aged care. The cohort recorded more severe
36 cognitive impairment than other international dementia registries.

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3 **37 Findings to date**
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7 **38** The cohort has so far been used to demonstrate a declining prevalence of dementia in
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10 **39** individuals entering the aged care sector, examine trends in psychotropic medicine
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14 **40** prescribing, and to examine the impact of dementia on aged care service use and outcomes.
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18 **41 Future plans**
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22 **42** The ROSA dementia cohort will be updated periodically and is a powerful resource both on its
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25 **43** own and as a contributor to the Australian dementia CQR. Integration of the ROSA dementia
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28 **44** cohort with the dementia CQR will ensure that people with dementia using aged care services
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31 **45** can benefit from the ongoing monitoring and benchmarking of care that a registry can provide.
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46 STRENGTHS AND LIMITATIONS OF THIS STUDY

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

55 INTRODUCTION

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

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

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4 72 However, many people with dementia or MCI may be diagnosed in other settings [7]. Given
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7 73 the high prevalence of dementia among those accessing government-subsidised aged care
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10 74 services [8], existing aged care assessment data has great potential to contribute to the
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13 75 capture of individuals into the ADNeT CQR. Approximately 47% of Australian residential care
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16 76 users and 21% of home care users have a recorded diagnosis of dementia [8]. It is estimated
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19 77 that aged care assessments conducted from 2009 to 2015 captured approximately 36% of the
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22 78 estimated total population of people with dementia in Australia (prevalent cases) at the end of
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26 79 2015 [9]. Therefore, understanding and studying the cohort with dementia captured within the
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29 80 aged care sector can significantly contribute to our understanding of the individuals that may
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32 81 not be captured earlier for a national CQR. Information about health service use, medicines,
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35 82 hospitalisations, mortality and other information can then be monitored for these individuals
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39 83 over time.

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42 84 In our current evaluation we have examined (a) the demographic and clinical features of
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45 85 people with dementia using Australian aged care services and the extent to which these are
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49 86 representative of the broader population of people with dementia in Australia, and (b) the
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52 87 comparability of data captured in aged care datasets to selected established international
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55 88 dementia registries. This will allow for better understanding of the characteristics and
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3 89 limitations of this cohort for monitoring the quality of care and outcomes for people living with
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11 91 **COHORT DESCRIPTION**
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15 92 **Design and data sources**
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19 93 A national cohort of all non-Indigenous Australians aged 65 and over who have accessed
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22 94 government-subsidised aged care services from 1997 to 2017 (and updated regularly) is
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25 95 captured in the Registry of Senior Australians (ROSA). In ROSA, national aged care
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28 96 assessment data are linked with information about aged care service use, health service use,
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31 97 medication dispensing, hospitalisations, and death records [10] of individuals that entered the
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34 98 aged care sector. Specifically, assessments within the aged care sector are conducted to
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37 99 determine eligibility for government-subsidised services (by Aged Care Assessment Teams,
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41 100 established in 2003; ACAT) or to identify funding requirements in residential aged care (Aged
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44 101 Care Funding Instrument, established in 2008; ACFI). In both assessments assessors are
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47 102 clinically-trained medical, nursing or allied health professionals who identify the level of care
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50 103 need based on functional and cognitive limitations [11,12]. Data from assessments, as well as
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53 104 aged care service use, are provided to ROSA from the Australian Institute of Health and
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57 105 Welfare National Aged Care Data Clearinghouse.
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4 106 These data are subsequently linked with information about government-subsidised health
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7 107 service use from the Medicare Benefits Schedule (MBS), medicine dispensing from the
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10 108 Pharmaceutical Benefits Scheme (PBS), state based hospital records and mortality data from
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13 109 the National Death Index (NDI). The ROSA established this cross-sector data linkage for
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16 110 research purposes and aims to assess the effectiveness, appropriateness, and quality of aged
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19 111 care services provided to older individuals over time. In its entirety, the historical ROSA cohort
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22 112 includes over 2.8 million individuals, including 1.2 million who have had aged care eligibility
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25 113 assessments for substantial aged care services like permanent residential care, home care
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29 114 packages, residential respite care and transition care.

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33 115 Ethical approval for ROSA was provided by the University of South Australia (reference
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36 116 ID200489), Australian Institute of Health and Welfare (reference EO2018/1/418), South
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39 117 Australian Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South
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42 118 Wales Population and Health Services (reference 2019/ETH12028) Human Research Ethics
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46 119 Committees.

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50 120 Here we present results of a cross-sectional evaluation of the people with dementia identified
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53 121 in aged care assessment data (hereafter referred to as the 'ROSA dementia cohort') between
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56 122 July 1 2008 and June 30 2016. The entry point to the ROSA dementia cohort is the first aged
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59 123 care assessment where a recording of dementia was made, though the person may have

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3 124 entered the ROSA with an earlier assessment (on which a dementia diagnosis was not
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6 125 recorded). Entry is distinct from the date of diagnosis, which will have occurred earlier and is
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10 126 not known for our cohort. Where a person is identified from medication prescribing records,
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13 127 data from the closest aged care assessment is included here for cohort profiling.
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17 128 **Dementia ascertainment**

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21 129 Dementia is determined from aged care eligibility assessments (conducted by ACAT),
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24 130 assessments for funding in permanent residential care (conducted using the ACFI), and from
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27 131 pharmaceutical data as captured in PBS. In assessments, assessors record up to 10 (ACAT)
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30 132 or up to three (ACFI) major diseases or disorders that have an impact on the person's need
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33 133 for assistance with activities of daily living and social participation, together with documented
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36 134 evidence of a diagnosis from a medical practitioner. Assessors can record one or more types
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40 135 of dementia or have the option to classify the dementia as 'unspecified' based on the medical
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43 136 record. In addition, medicines prescribed for the treatment of Alzheimer's disease are not
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46 137 dispensed for any other reason. Any person with who has been dispensed donepezil
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49 138 (Anatomical Therapeutic Chemical Classification System code, ATC N06DA02), galantamine
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52 139 (ATC code N06DA04), rivastigmine (ATC code N06DA03) or memantine (ATC code
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55 140 N06DX01) can be classified as having dementia.
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3 141 **Minimum data set**
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7 142 The data available for the ROSA dementia cohort is presented in Table 1, with comparable
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10 143 data from other established dementia registries. Registries included for comparison were
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14 144 chosen based on their broad coverage and the availability of data for comparison here. They
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17 145 include one clinical quality registry (the Swedish Dementia Registry (SveDem)), and two
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20 146 epidemiological dementia registries (French National Alzheimer Database (BNA); Registry of
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23 147 Dementia of Girona, Spain (ReDeGi)).
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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 Girona [15]
Country	Australia	Sweden	France	Spain ^a
Demographics	Date of birth	Age	Date of birth	Date of birth
	Sex	Sex	Sex	Sex
	Living arrangements	Living arrangements	Living arrangements	Living arrangement
	Country of birth	Driver's licence (y/n)	Area of birth	Nationality
	Language	Weapons licence (y/n)	Education	Region
	Region			Occupation
	Marital status			Education
	Socioeconomic status			Marital status
	^b			
	Carer availability			
Carer relationship				
Carer co-residency (y/n)				
Clinical characteristics	Type of dementia	Type of dementia	Type of dementia	Type of dementia
		Family history of dementia	Procedure type ^c	Family history of dementia
		BMI		Aged at symptom onset (estimated)
		Total number of diagnostic tests		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: <ul style="list-style-type: none"> • 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)

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		Cardiovascular drugs (y/n)	Serious drug-related adverse event (y/n)	
		Total number of drugs		
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

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

152 ^a Regional only - Girona

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

154 ^c Consultation, neuropsychological assessment, day-hospital visit, or group session

155 ^d PRAC only

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

159 ^f Government-subsidised medicines only

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

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4 161 ROSA includes comprehensive demographic data and information about aged and health care
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7 162 service use, including service entry and exit dates. All prescription-based medicine dispensing
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10 163 is recorded by the PBS, facilitating monitoring of medicine dosage, duration, and
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13 164 polypharmacy. Information about family history of dementia, diagnostic procedures, or other
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16 165 clinical details (aside from comorbidities) is not available. ROSA also does not include
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19 166 privately-funded health service use.

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23 167 Assessments conducted for financial purposes at entry into residential aged care are repeated
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26 168 when care needs change. These include a standardised neuropsychological assessment.

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30 169 While most dementia registries include the Mini-Mental Status Examination (MMSE), copyright
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33 170 restrictions have precluded its widespread clinical use in Australia. Instead, the
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36 171 Psychogeriatric Assessment Scale-Cognitive Impairment Scale (PAS-CIS) [19] is conducted
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39 172 where cognitive impairment is suspected or known. The PAS-CIS correlates strongly with the
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42 173 MMSE [20]. A Cornell Scale for Depression (CSD) [21] is conducted where symptoms of
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45 174 depression and dysthymia are present. Functional dependence is rated across domains
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49 175 (including nutrition, mobility, personal hygiene, toileting, continence, home maintenance, and
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52 176 transport) though a validated measure like those used in other registries is not included.

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56 177 **Cohort characteristics**
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4 178 There were 363,695 people in the ROSA dementia cohort over the capture period (Table 2).
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7 179 Detailed demographic data on the cohort appears in Supplementary Table 1. The cohort is
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10 180 representative of the geographical spread of the Australian population with the majority living
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13 181 in New South Wales, Victoria, and Queensland (76.2%, compared to 77.4% of the general
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16 182 population). Similarly, 33.4% of the ROSA dementia cohort live outside a major city
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19 183 (compared to 28.2% of the general population), 32.9% were born outside Australia (compared
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22 184 to 33.3% of the general population), and 11.5% primarily speak a language other than English
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26 185 (compared to 22.2% of general population households where a non-English language is
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29 186 spoken) [22]. While comparable on sex, the ROSA dementia cohort is older at entry than other
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32 187 registries and includes more people living in permanent residential care.
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188 Table 2. Comparison of the ROSA Dementia Cohort and International Dementia Registries, Demographic Characteristics

	ROSA Dementia Cohort <i>n</i> =373,695	Swedish Dementia Registry [13] <i>n</i> =28,722 ^a	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14,23] <i>n</i> =193,729 ^b	Registry of Dementia for Girona [15] <i>n</i> =277
Age at cohort entry (\bar{x} , 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 (63.6)
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			(<i>n</i> =341,498) ^b	
Lives alone	72,392 (19.4)	25,492 (88.8) ^c	32,034 (9.4)	505 (82.6) ^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)

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

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

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

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192 ^b Includes 147,769 people with other diagnoses (psychiatric disorders, subjective memory complaints, other neurological
193 disorders, diagnoses pending)
194 ^c Living in community

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4 195 Alzheimer's disease (AD) is the most common type of dementia in ROSA, similarly to other
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7 196 registries examined (Table 3). On cognitive assessment, which are only completed by those
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10 197 living in permanent residential care (82% of the cohort had a PAS-CIS score available), the
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13 198 ROSA cohort were more cognitively impaired than the cohorts of other registries.
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199 Table 3. Comparison of the ROSA Dementia Cohort and international dementia registries on clinical characteristics

	ROSA Dementia Cohort <i>n</i> =309,958 ^a	Swedish Dementia Registry [13] <i>n</i> =28,722	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14,23] <i>n</i> =193,729	Registry of Dementia for Girona [15] <i>n</i> =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	MMS 16.8 (4.4)
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)

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3 200 AD=Alzheimer's disease; CDRS=Clinical Dementia Rating Scale; MCI=Mild cognitive impairment; MMSE=Mini-mental Status examination [17];
4 201 NA=Not available; PAS-CIS=Psychogeriatric Assessment Scales-Cognitive Impairment Scale; ROSA=Registry of Senior Australians; SD=Standard
5 202 deviation.
6
7 203 ^a From residential care funding assessments (*n*=63,737 without these assessment data not included)
8 204 ^b Vascular dementia, dementia in other disease, mixed type, other dementias, unspecified dementia
9 205 ^c 'Diagnosis pending' *n*=69,355
10 206 ^d *n*=212,156; PAS-CIS at times not conducted due to severe cognitive impairment, speech impairments, language differences, sensory impairments, or refusal

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4 207 People in the ROSA dementia cohort have a median four (interquartile range=2) other
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7 208 comorbid health conditions. In SveDem, people with dementia recorded a median Charlson
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10 209 comorbid index score of 2 (IQR=2) [24]. In the ROSA dementia cohort, the most common
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13 210 comorbid conditions were hypertension arthritis (35.0%), hypertension (34.9%), and heart
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16 211 diseases (31.7%%). Cerebrovascular disease (15.5%) and hypercholesterolemia (9.1%) were
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19 212 common. Prevalence of hypertension and hypercholesterolemia were lower than the Spanish
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22 213 ReDeGi registry (50.6% and 25.1%, respectively) ,). Prevalence of cerebrovascular disease
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26 214 in our cohort was similar to ReDeGi [15]. In our cohort, more than 99% of individuals reported
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29 215 at least one activity limitation, most often transport (94.7%), health care tasks (92.7%) and
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32 216 social and community participation (92.5%). Individuals in the ROSA dementia cohort lived for
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35 217 an average of two years after they were first identified with dementia in the aged care
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38 218 assessment data and were on average 88 years old (SD=6.6 years) at the time of their deaths.
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42 219 In contrast, a recent analysis of the SveDem cohort identified that only 28% of the cohort had
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45 220 died within the median 2-year follow up period [25]. In ROSA, dementia was recorded as the
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48 221 primary cause of death for 27% of the cohort, most commonly unspecified dementia (15.2%).
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51 222 Other common causes of death were heart diseases (21.8%) and cerebrovascular disease
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54 223 (21.1%).

224 Patient and Public Involvement

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4 225 Consumer representatives are part of the governance structure of ROSA, and provided
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7 226 oversight for ROSA's development and now oversee ongoing operations.
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10 227 **FINDINGS TO DATE**

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15 228 To date, the ROSA dementia cohort has been used to demonstrate a declining prevalence of
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18 229 dementia in individuals entering the aged care sector [8], to determine that there is a higher
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21 230 prescribing of psychotropic medicines in people with dementia in residential care, to show the
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24 231 value of residential respite for delaying institutionalisation for people with dementia [26], and
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27 232 to highlight poorer outcomes after hip fracture among those with pre-morbid dementia than
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30 233 without dementia [27]. The broader ROSA dataset has also recently been used to develop an
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34 234 Outcome Monitoring System for aged care, with 12 indicators of care quality that can be
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37 235 monitored over time and across geographical areas [28]. Most of these indicators are relevant
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40 236 to dementia care, including psychotropic medicine use, hospitalisations, and falls, and work is
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43 237 underway to apply them to the monitoring of care in the ROSA dementia cohort.
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47 238 **STRENGTHS AND LIMITATIONS**

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51 239 The large sample and national coverage provided by ROSA are key strengths of the ROSA
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54 240 dementia cohort. ROSA includes the largest existing population-based sample of people with
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58 241 dementia in Australia and is representative of the population in many ways, including sex,
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4 242 regionality, and cultural and linguistic diversity. An average of 37,661 new cases of dementia
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7 243 are identified in ROSA each year and many of these may not be identified via other sources
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10 244 [9]. The ROSA dementia cohort is therefore a powerful resource both on its own and as a
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13 245 contributor to the ADNeT CQR [6]. A wide breadth of data is available in ROSA and this is
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16 246 expanding as linkage to new state-based data sources continues, including hospitalisations
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19 247 and ambulance use. These data can facilitate monitoring of clinical care and determinants of
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23 248 important outcomes including institutionalisation and mortality over time.

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27 249 Despite these benefits, there are important limitations to the ROSA dementia cohort. First, we
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30 250 cannot capture people with dementia who do not have a diagnosis, nor those who do not
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33 251 access aged care services. Approximately half of people with dementia in Australia are
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36 252 estimated to receive a diagnosis [7,29,30], and delays in diagnosis are common [7,31]. People
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39 253 who do receive a diagnosis tend to have more severe impairment, have insight into their
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43 254 impairment, speak English, live in metropolitan areas and in areas with greater access to
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46 255 health services, have higher levels of education, and be married [32]. Also, one in three
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49 256 women and one in two men will not use an aged care service in their lifetime [33]; ROSA is
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52 257 not able to capture these individuals and these factors introduce a sampling bias to our cohort.
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56 258 Second, two important groups are not represented in the current ROSA cohort. People who
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59 259 accessed aged care services before 65 years of age but died before turning 65 years old are

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4 260 not included. We estimate that ROSA currently captures 40-84% of those aged under 65 using
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7 261 aged care (depending on the year). The number of missing cases of dementia attributable to
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10 262 this data gap is likely to be small given that most people with symptom onset prior to 65 years
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13 263 are aged 60-64 years at onset and will age over 65 years with their condition [34]. Nonetheless,
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16 264 types of dementia that are most common in younger groups (for example alcohol-related
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19 265 dementias, frontotemporal dementias, dementia in Huntington's disease, dementia in Down
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22 266 syndrome) are likely to be underrepresented. ROSA also does not currently include Aboriginal
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26 267 and Torres Strait Islander people, though consultation is under way to enable inclusion of this
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29 268 cohort in future analyses.

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33 269 Third, the data available in ROSA is not collected for research purposes and therefore may
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36 270 have limited internal validity. While the 'breadth' of data is a key strength of this cohort, its
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39 271 relative lack of 'depth' is a limitation and the suitability of service use is difficult to assess. The
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42 272 accuracy of clinical and demographic data also relies on assessors who are not necessarily
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46 273 trained in research data collection or in dementia care. Aged care assessors are limited to
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49 274 recording a maximum of 10 health conditions (ACAT) or three mental/cognitive conditions
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52 275 (ACFI) per assessment; whether dementia is considered an important enough comorbidity to
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55 276 be listed is at the assessors' discretion. In the absence of cognitive assessment, the accuracy
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58 277 of the dementia diagnosis recorded in ROSA is dependent on the skills and resources
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3 278 available to the clinician who made the diagnosis. Additionally, ROSA is not a dementia-
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6 279 specific registry and includes fewer clinical details than available in other cohorts.
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10 280 Finally, aged care eligibility assessments can occur sometime after dementia symptom onset
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13 281 or formal diagnosis, limiting the potential for monitoring early clinical care. More than 36% of
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16 282 individuals entered the ROSA dementia cohort at entry to or while living in residential aged
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19 283 care, which is likely to be late in their disease path. As such, people living in permanent
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22 284 residential care are overrepresented in ROSA compared to national estimates [5] and to other
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25 285 registries that recruit at the time of diagnosis. They are also likely to have more functional
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28 286 limitations and comorbid health conditions and to die sooner than other registries, though little
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31 287 data from other registries is available for comparison. Capture of those entering residential
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34 288 care for a dementia CQR is nonetheless important given that many will not be identified
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43 290 **COLLABORATION**

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47 291 ROSA is the product of a consortium of 13 academic, clinical, industry, consumer
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50 292 representative and public health organisations [10]. The consortium oversees ROSA
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53 293 management and use, ensuring that ROSA projects have clinical and public health relevance.
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56 294 Results described here demonstrate that aged care assessment data can be a valuable
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3 295 resource for maximising capture for the ADNeT CQR. Linkage between ROSA and ADNeT
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6 296 will ensure both that monitoring of care can occur early in the disease course, and that people
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9 297 with dementia using aged care services can benefit from the ongoing monitoring and
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13 298 benchmarking of their clinical care.
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17 299 **AUTHOR CONTRIBUTIONS**

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21 300 MC, MCr, and SW conceptualised the project, obtained funding, and assisted with reviewing
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23
24 301 and editing the manuscript. MCa drafted, reviewed, and edited the manuscript. MCa and CL
25
26
27 302 conducted data analysis. CW and JM provided oversight to the project and assisted with
28
29
30 303 manuscript review and editing. All authors read and approved the final manuscript.
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40
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45
46
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49
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51
52
53 310 had no role in study design, methods, data collection and analysis, decision to publish or
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3 311 preparation of this manuscript. All authors had final responsibility for the decision to submit for
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6 312 publication.
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10 313 **CONFLICTS OF INTEREST**
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14 314 MCA has been employed in the last five years to assist with data collection for drug trials
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18 315 funded by Janssen and Merck. All other authors declare no conflicts of interest.
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22 316 **ETHICAL APPROVAL**
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26 317 Ethical approval was provided by the University of South Australia (reference ID200489),
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35 320 Population and Health Services (reference 2019/ETH12028) Human Research Ethics
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38 321 Committees.
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48
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51
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55
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58
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60

1
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4
5
6 329 also like to thank the ADNeT Registry Steering Committee for providing governance oversight,
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8
9
10 330 strategic direction and advice to the ADNeT Registry project.
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14 331 **DATA AVAILABILITY STATEMENT**
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18 332 Researchers interested in collaboration are invited to contact the research team to access the
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21 333 data available in ROSA. In addition to the data described here, similar data is available from
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24 334 aged care users without dementia, and state-based hospitalisation data for some Australian
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27 335 states. Data linkage is ongoing and is being updated over time.
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3 **SUPPLEMENTARY MATERIALS**
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5 Supplementary Table 1. The ROSA Dementia Cohort Comprehensive Demographic and Clinical
6 Characteristics

	<i>n</i> (%)	
	All (<i>n</i> =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 (<i>n</i> =214,780)		
	Has carer	185,118 (86.2)
	No carer	14,781 (6.9)
	Missing	14,836 (6.9)

		<i>n</i> (%)
		All (<i>n</i> =373,695)
Carer relationship ^b (<i>n</i> =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 (<i>n</i> =185,118)		
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		
	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 (<i>n</i> =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 (<i>n</i> =122,253) (mean, SD)		
Dead at June 30 2016		249.682 (66.8)
Age at death (<i>n</i> =249,682) (mean, SD)		87.5 (6.6)
Years from cohort entry to death (<i>n</i> =249,682) (mean, SD)		2.1 (1.7)
Primary cause of death (<i>n</i> =249,682)		
	Circulatory disease	87,604 (35.1)
	Heart disease	54,412 (21.8)
	Cerebrovascular disease	30,246 (21.1)

		<i>n</i> (%)
		All (<i>n</i> =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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1 **TITLE**

2 Cohort profile: Dementia in the Registry of Senior Australians

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19 **WORD COUNT**

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21 ABSTRACT

22 Purpose

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

32 Participants

33 There were 373,695 people with dementia identified in aged care assessments from 2008 to
34 2016. Cross-sectional analysis from the time of cohort entry (e.g. when first identified with
35 dementia on an aged care assessment) indicates that individuals were 84.1 years old on
36 average , and 63.1% were female. More than 44% were first identified at entry to permanent

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3 37 residential aged care. The cohort recorded more severe cognitive impairment at entry than
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6 38 other international dementia registries.
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10 39 **Findings to date**

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14 40 The cohort has so far been used to demonstrate a declining prevalence of dementia in
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18 41 individuals entering the aged care sector, examine trends in psychotropic medicine
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21 42 prescribing, and to examine the impact of dementia on aged care service use and outcomes.
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25 43 **Future plans**

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29 44 The ROSA dementia cohort will be updated periodically and is a powerful resource both on its
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32 45 own and as a contributor to the Australian dementia CQR. Integration of the ROSA dementia
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35 46 cohort with the dementia CQR will ensure that people with dementia using aged care services
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38 47 can benefit from the ongoing monitoring and benchmarking of care that a registry can provide.
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48 STRENGTHS AND LIMITATIONS OF THIS STUDY

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

57 INTRODUCTION

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

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

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4 74 However, many people with dementia or MCI may be diagnosed in other settings [7]. Given
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7 75 the high prevalence of dementia among those accessing government-subsidised aged care
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10 76 services [8], existing aged care assessment data has great potential to contribute to the
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13 77 capture of individuals into the ADNeT CQR. Approximately 47% of Australian residential care
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16 78 users and 21% of home care users have a recorded diagnosis of dementia [8]. It is estimated
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19 79 that aged care assessments conducted from 2009 to 2015 captured approximately 36% of the
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23 80 estimated total population of people with dementia in Australia (prevalent cases) at the end of
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26 81 2015 [9]. Therefore, understanding and studying the cohort with dementia captured within the
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29 82 aged care sector can significantly contribute to our understanding of the individuals that may
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32 83 not be captured earlier for a national CQR. Information about health service use, medicines,
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35 84 hospitalisations, mortality and other information can then be monitored for these individuals
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39 85 over time.

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42 86 In our current evaluation we have examined (a) the demographic and clinical features of
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45 87 people with dementia using Australian aged care services and the extent to which these are
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49 88 representative of the broader population of people with dementia in Australia, and (b) the
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52 89 comparability of data captured in aged care datasets to selected established international
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55 90 dementia registries. This will allow for better understanding of the characteristics and
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3 91 limitations of this cohort for monitoring the quality of care and outcomes for people living with
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10 93 **COHORT DESCRIPTION**
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14 94 **Design and data sources**
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18 95 A national cohort of all non-Indigenous Australians aged 65 and over who have accessed
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21 96 government-subsidised aged care services from 1997 to 2017 (and updated regularly) is
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25 97 captured in the Registry of Senior Australians (ROSA). In ROSA, national aged care
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28 98 assessment data are linked with information about aged care service use, health service use,
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31 99 medication dispensing, hospitalisations, and death records [10] of individuals that entered the
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35 100 aged care sector. Specifically, assessments within the aged care sector are conducted to
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38 101 determine eligibility for government-subsidised services (by Aged Care Assessment Teams,
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41 102 established in 2003; ACAT) or to identify funding requirements in residential aged care (Aged
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44 103 Care Funding Instrument, established in 2008; ACFI). In both assessments assessors are
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47 104 clinically-trained medical, nursing or allied health professionals who identify the level of care
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50 105 need based on functional and cognitive limitations [11,12]. Data from assessments, as well as
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54 106 aged care service use, are provided to ROSA from the Australian Institute of Health and
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57 107 Welfare National Aged Care Data Clearinghouse.
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4 108 These data are subsequently linked with information about government-subsidised health
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7 109 service use from the Medicare Benefits Schedule (MBS), medicine dispensing from the
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10 110 Pharmaceutical Benefits Scheme (PBS), state-based hospital records and mortality data from
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13 111 the National Death Index (NDI). The ROSA established this cross-sector data linkage for
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16 112 research purposes and aims to assess the effectiveness, appropriateness, and quality of aged
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19 113 care services provided to older individuals over time. In its entirety, the historical ROSA cohort
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22 114 includes over 2.8 million individuals, including 1.2 million who have had aged care eligibility
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25 115 assessments for substantial aged care services like permanent residential care, home care
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29 116 packages, residential respite care and transition care.

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33 117 Ethical approval for ROSA was provided by the University of South Australia (reference
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36 118 ID200489), Australian Institute of Health and Welfare (reference EO2018/1/418), South
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39 119 Australian Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South
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43 120 Wales Population and Health Services (reference 2019/ETH12028) Human Research Ethics
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46 121 Committees.

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50 122 Here we present results of a cross-sectional evaluation of the people with dementia identified
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53 123 in aged care assessment data (hereafter referred to as the 'ROSA dementia cohort') between
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56 124 July 1 2008 and June 30 2016. The entry point to the ROSA dementia cohort is the first aged
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59 125 care assessment where a recording of dementia was made, though the person may have

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3 126 entered the ROSA with an earlier assessment (on which a dementia diagnosis was not
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6 127 recorded). Entry is distinct from the date of diagnosis, which will have occurred earlier and is
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10 128 not known for our cohort. Where a person is identified from medication prescribing records,
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13 129 data from the closest aged care assessment is included here for cohort profiling.
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17 130 **Dementia ascertainment**

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21 131 Dementia is determined from aged care eligibility assessments (conducted by ACAT),
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24 132 assessments for funding in permanent residential care (conducted using the ACFI), and from
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27 133 pharmaceutical data as captured in PBS. In assessments, assessors record up to 10 (ACAT)
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30 134 or up to three (ACFI) major diseases or disorders that have an impact on the person's need
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33 135 for assistance with activities of daily living and social participation, together with documented
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36 136 evidence of a diagnosis from a medical practitioner. Assessors can record one or more types
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40 137 of dementia or have the option to classify the dementia as 'unspecified' based on the medical
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43 138 record. In addition, medicines prescribed for the treatment of Alzheimer's disease are not
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46 139 dispensed for any other reason. Any person with who has been dispensed donepezil
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49 140 (Anatomical Therapeutic Chemical Classification System code, ATC N06DA02), galantamine
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52 141 (ATC code N06DA04), rivastigmine (ATC code N06DA03) or memantine (ATC code
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55 142 N06DX01) can be classified as having dementia.
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3 143 **Minimum data set**
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7 144 The data available for the ROSA dementia cohort is presented in Table 1, with comparable
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10 145 data from other established dementia registries. Registries included for comparison were
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14 146 chosen based on their broad coverage and the availability of data for comparison here. They
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17 147 include one clinical quality registry (the Swedish Dementia Registry (SveDem)), and two
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20 148 epidemiological dementia registries (French National Alzheimer Database (BNA); Registry of
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23 149 Dementia of Girona, Spain (ReDeGi)).
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150 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	Age	Date of birth	Date of birth
	Sex	Sex	Sex	Sex
	Living arrangements	Living arrangements	Living arrangements	Living arrangement
	Country of birth	Driver's licence (y/n)	Area of birth	Nationality
	Language	Weapons licence (y/n)	Education	Region
	Region			Occupation
	Marital status			Education
	Socioeconomic status			Marital status
	^b			
	Carer availability			
Carer relationship				
Carer co-residency (y/n)				
Clinical characteristics	Type of dementia	Type of dementia	Type of dementia	Type of dementia
		Family history of dementia	Procedure type ^c	Family history of dementia
		BMI		Aged at symptom onset (estimated)
		Total number of diagnostic tests		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: <ul style="list-style-type: none"> • 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)

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		Cardiovascular drugs (y/n)	Serious drug-related adverse event (y/n)	
		Total number of drugs		
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

151 BDRS=Blessed Dementia Rating Scale ; BMI=Body mass index; CDRS=Clinical Dementia Rating Scale; IADL=Instrumental Activities of Daily Living [16];

152 MMSE=Mini-mental Status Examination [17]; NA=Not available;; PAS-CIS=Psychogeriatric Assessment Scale-Cognitive Impairment Scale; PRAC=Permanent
153 residential aged care; QUALID=Quality of Life in Late-Stage Dementia scale [18]; SD=Standard deviation.

154 ^a Regional only - Girona

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

156 ^c Consultation, neuropsychological assessment, day-hospital visit, or group session

157 ^d PRAC only

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

160 ^f Government-subsidised medicines only

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

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4 162 ROSA includes comprehensive demographic data and information about aged and health care
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7 163 service use, including service entry and exit dates. All prescription-based medicine dispensing
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10 164 is recorded by the PBS, facilitating monitoring of medicine dosage, duration, and
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13 165 polypharmacy. Information about family history of dementia, diagnostic procedures, or other
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16 166 clinical details (aside from comorbidities) is not available. ROSA also does not include
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19 167 privately-funded health service use.

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23 168 Assessments conducted for financial purposes at entry into residential aged care are repeated
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26 169 when care needs change. These include a standardised neuropsychological assessment.

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30 170 While most dementia registries include the Mini-Mental Status Examination (MMSE), copyright
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33 171 restrictions have precluded its widespread clinical use in Australia. Instead, the
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36 172 Psychogeriatric Assessment Scale-Cognitive Impairment Scale (PAS-CIS) [19] is conducted
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39 173 where cognitive impairment is suspected or known. The PAS-CIS correlates strongly with the
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42 174 MMSE [20]. A Cornell Scale for Depression (CSD) [21] is conducted where symptoms of
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45 175 depression and dysthymia are present. Functional dependence is rated across domains
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48 176 (including nutrition, mobility, personal hygiene, toileting, continence, home maintenance, and
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51 177 transport) though a validated measure like those used in other registries is not included.

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56 178 **Cohort characteristics**
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4 179 There were 363,695 people in the ROSA dementia cohort over the capture period (Table 2).
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7 180 Detailed demographic data on the cohort appears in Supplementary Table 1. The cohort is
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10 181 representative of the geographical spread of the Australian population with the majority living
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13 182 in New South Wales, Victoria, and Queensland (76.2%, compared to 77.4% of the general
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16 183 population). Similarly, 33.4% of the ROSA dementia cohort live outside a major city
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19 184 (compared to 28.2% of the general population), 32.9% were born outside Australia (compared
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22 185 to 33.3% of the general population), and 11.5% primarily speak a language other than English
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25 186 (compared to 22.2% of general population households where a non-English language is
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28 187 spoken) [22]. While comparable on sex, the ROSA dementia cohort is older at entry than other
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32 188 registries and includes more people living in permanent residential care.
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189 Table 2. Comparison of the ROSA Dementia Cohort and International Dementia Registries, Demographic Characteristics

	ROSA Dementia Cohort <i>n</i> =373,695	Swedish Dementia Registry [13] <i>n</i> =28,722 ^a	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14,23] <i>n</i> =193,729 ^b	Registry of Dementia for Girona [15] <i>n</i> =277
Age at cohort entry (\bar{x} , 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 (63.6)
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			(<i>n</i> =341,498) ^b	
Lives alone	72,392 (19.4)	25,492 (88.8) ^c	32,034 (9.4)	505 (82.6) ^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)

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

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

192 ^a Figures published in 2015; the registry included 81,152 individuals in October 2018 (www.ucl.ac.uk/med/psychiatry/units/psychogeriatrics/)

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193 ^b Includes 147,769 people with other diagnoses (psychiatric disorders, subjective memory complaints, other neurological
194 disorders, diagnoses pending)
195 ^c Living in community

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4 196 Alzheimer's disease (AD) is the most common type of dementia in ROSA, similarly to other
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7 197 registries examined (Table 3). On cognitive assessment, which are only completed by those
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10 198 living in permanent residential care (82% of the cohort had a PAS-CIS score available), the
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13 199 ROSA cohort were more cognitively impaired than the cohorts of other registries.
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200 Table 3. Comparison of the ROSA Dementia Cohort and international dementia registries on clinical characteristics

	ROSA Dementia Cohort <i>n</i> =309,958 ^a	Swedish Dementia Registry [13] <i>n</i> =28,722	Banque Nationale Alzheimer (National Alzheimer's Data Bank) [14,23] <i>n</i> =193,729	Registry of Dementia for Girona [15] <i>n</i> =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	MMS 16.8 (4.4)
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)

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3 201 AD=Alzheimer's disease; CDRS=Clinical Dementia Rating Scale; MCI=Mild cognitive impairment; MMSE=Mini-mental Status examination [17];
4 202 NA=Not available; PAS-CIS=Psychogeriatric Assessment Scales-Cognitive Impairment Scale; ROSA=Registry of Senior Australians; SD=Standard
5 203 deviation.
6
7 204 ^a From residential care funding assessments (*n*=63,737 without these assessment data not included)
8 205 ^b Vascular dementia, dementia in other disease, mixed type, other dementias, unspecified dementia
9 206 ^c 'Diagnosis pending' *n*=69,355
10 207 ^d *n*=212,156; PAS-CIS at times not conducted due to severe cognitive impairment, speech impairments, language differences, sensory impairments, or refusal
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4 208 People in the ROSA dementia cohort have a median four (interquartile range=2) other
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7 209 comorbid health conditions. In SveDem, people with dementia recorded a median Charlson
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10 210 comorbid index score of 2 (IQR=2) [24]. In the ROSA dementia cohort, the most common
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13 211 comorbid conditions were arthritis (35.0%), hypertension (34.9%), and heart diseases
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16 212 (31.7%%). Cerebrovascular disease (15.5%) and hypercholesterolemia (9.1%) were common.
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19 213 Prevalence of hypertension and hypercholesterolemia were lower than the Spanish ReDeGi
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22 214 registry (50.6% and 25.1%, respectively). Prevalence of cerebrovascular disease in our cohort
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26 215 was similar to ReDeGi [15]. In our cohort, more than 99% of individuals reported at least one
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29 216 activity limitation, most often transport (94.7%), health care tasks (92.7%) and social and
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32 217 community participation (92.5%). Individuals in the ROSA dementia cohort lived for an
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35 218 average of two years after they were first identified with dementia in the aged care assessment
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38 219 data and were on average 88 years old (SD=6.6 years) at the time of their deaths. In contrast,
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42 220 a recent analysis of the SveDem cohort identified that only 28% of the cohort had died within
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45 221 the median 2-year follow up period [25]. In ROSA, dementia was recorded as the primary
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48 222 cause of death for 27% of the cohort, most commonly unspecified dementia (15.2%). Other
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51 223 common causes of death were heart diseases (21.8%) and cerebrovascular disease (21.1%).
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55 224 Patient and Public Involvement

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4 225 Consumer representatives are part of the governance structure of ROSA and provided
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7 226 oversight for ROSA's development and now oversee ongoing operations.
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10 227 **FINDINGS TO DATE**

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14 228 To date, the ROSA dementia cohort has been used to demonstrate a declining prevalence of
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17 229 dementia in individuals entering the aged care sector [8], to determine that there is a higher
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21 230 prescribing of psychotropic medicines in people with dementia in residential care, to show the
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24 231 value of residential respite for delaying institutionalisation for people with dementia [26], and
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27 232 to highlight poorer outcomes after hip fracture among those with pre-morbid dementia than
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31 233 without dementia [27]. The broader ROSA dataset has also recently been used to develop an
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34 234 Outcome Monitoring System for aged care, with 12 indicators of care quality that can be
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37 235 monitored over time and across geographical areas [28]. Most of these indicators are relevant
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40 236 to dementia care, including psychotropic medicine use, hospitalisations, and falls, and work is
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43 237 underway to apply them to the monitoring of care in the ROSA dementia cohort.
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47 238 **STRENGTHS AND LIMITATIONS**

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51 239 The large sample and national coverage provided by ROSA are key strengths of the ROSA
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54 240 dementia cohort. ROSA includes the largest existing population-based sample of people with
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58 241 dementia in Australia and is representative of the population in many ways, including sex,
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4 242 regionality, and cultural and linguistic diversity. An average of 37,661 new cases of dementia
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7 243 are identified in ROSA each year and many of these may not be identified via other sources
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10 244 [9]. The ROSA dementia cohort is therefore a powerful resource both on its own and as a
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13 245 contributor to the ADNeT CQR [6]. A wide breadth of data is available in ROSA and this is
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16 246 expanding as linkage to new state-based data sources continues, including hospitalisations
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19 247 and ambulance use. These data can facilitate monitoring of clinical care and determinants of
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23 248 important outcomes including institutionalisation and mortality over time.

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27 249 Despite these benefits, there are important limitations to the ROSA dementia cohort. First, we
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30 250 cannot capture people with dementia who do not have a diagnosis, nor those who do not
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33 251 access aged care services. Approximately half of people with dementia in Australia are
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36 252 estimated to receive a diagnosis [7,29,30], and delays in diagnosis are common [7,31]. People
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39 253 who do receive a diagnosis tend to have more severe impairment, have insight into their
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43 254 impairment, speak English, live in metropolitan areas and in areas with greater access to
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46 255 health services, have higher levels of education, and be married [32]. Also, one in three
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49 256 women and one in two men will not use an aged care service in their lifetime [33]; ROSA is
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52 257 not able to capture these individuals and these factors introduce a sampling bias to our cohort.
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56 258 Second, two important groups are not represented in the current ROSA cohort. People who
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59 259 accessed aged care services before 65 years of age but died before turning 65 years old are

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4 260 not included. We estimate that ROSA currently captures 40-84% of those aged under 65 using
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7 261 aged care (depending on the year). The number of missing cases of dementia attributable to
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10 262 this data gap is likely to be small given that most people with symptom onset prior to 65 years
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13 263 are aged 60-64 years at onset and will age over 65 years with their condition [34]. Nonetheless,
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16 264 types of dementia that are most common in younger groups (for example alcohol-related
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19 265 dementias, frontotemporal dementias, dementia in Huntington's disease, dementia in Down
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22 266 syndrome) are likely to be underrepresented. ROSA also does not currently include Aboriginal
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26 267 and Torres Strait Islander people, though consultation is under way to enable inclusion of this
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29 268 cohort in future analyses.

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33 269 Third, the data available in ROSA is not collected for research purposes and therefore may
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36 270 have limited internal validity. While the 'breadth' of data is a key strength of this cohort, its
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39 271 relative lack of 'depth' is a limitation and the suitability of service use is difficult to assess. The
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42 272 accuracy of clinical and demographic data also relies on assessors who are not necessarily
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46 273 trained in research data collection or in dementia care. Aged care assessors are limited to
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49 274 recording a maximum of 10 health conditions (ACAT) or three mental/cognitive conditions
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52 275 (ACFI) per assessment; whether dementia is considered an important enough comorbidity to
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55 276 be listed is at the assessors' discretion. In the absence of cognitive assessment, the accuracy
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58 277 of the dementia diagnosis recorded in ROSA is dependent on the skills and resources
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3 278 available to the clinician who made the diagnosis. Additionally, ROSA is not a dementia-
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6 279 specific registry and includes fewer clinical details than available in other cohorts.
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10 280 Finally, aged care eligibility assessments can occur sometime after dementia symptom onset
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13 281 or formal diagnosis, limiting the potential for monitoring early clinical care. More than 36% of
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16 282 individuals entered the ROSA dementia cohort at entry to or while living in residential aged
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19 283 care, which is likely to be late in their disease path. As such, people living in permanent
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22 284 residential care are overrepresented in ROSA compared to national estimates [5] and to other
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25 285 registries that recruit at the time of diagnosis. They are also likely to have more functional
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28 286 limitations and comorbid health conditions and to die sooner than other registries, though little
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31 287 data from other registries is available for comparison. Capture of those entering residential
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34 288 care for a dementia CQR is nonetheless important given that many will not be identified
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43 290 **COLLABORATION**

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47 291 ROSA is the product of a consortium of 13 academic, clinical, industry, consumer
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50 292 representative and public health organisations [10]. The consortium oversees ROSA
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53 293 management and use, ensuring that ROSA projects have clinical and public health relevance.
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56 294 Results described here demonstrate that aged care assessment data can be a valuable
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4 295 resource for maximising capture for the ADNeT CQR. Linkage between ROSA and ADNeT
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7 296 will ensure both that monitoring of care can occur early in the disease course, and that people
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10 297 with dementia using aged care services can benefit from the ongoing monitoring and
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13 298 benchmarking of their clinical care.

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17 299 Other collaboration is welcomed, and researchers interested in collaboration are invited to
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20 300 contact the research team to access all data available in ROSA. In addition to the data
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23 301 described here, similar data is available from aged care users without dementia and state-
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26 302 based hospitalisation data for some Australian states. Data linkage is ongoing and is being
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29 303 updated over time, and we particularly encourage collaboration with those with other datasets
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33 304 that could be linked. Data access is subject to ethical and governance approval.
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36 37 305 **AUTHOR CONTRIBUTIONS**

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41 306 MI, MCr, and SW conceptualised the project, obtained funding, and assisted with reviewing
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43
44 307 and editing the manuscript. MCa drafted, reviewed, and edited the manuscript. MCa and CL
45
46
47 308 conducted data analysis. CW and JM provided oversight to the project and assisted with
48
49
50 309 manuscript review and editing. All authors read and approved the final manuscript.
51
52

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13
14 315 The Hospital Research Foundation. The funders had no role in study design, methods, data
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16
17 316 collection and analysis, decision to publish or preparation of this manuscript. All authors had
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20 317 final responsibility for the decision to submit for publication.
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25 318 **CONFLICTS OF INTEREST**

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29 319 MCa has been employed in the last five years to assist with data collection for drug trials
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32 320 funded by Janssen and Merck. All other authors declare no conflicts of interest.
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36 321 **ETHICAL APPROVAL**

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40 322 Ethical approval was provided by the University of South Australia (reference ID200489),
41
42
43 323 Australian Institute of Health and Welfare (reference EO2018/1/418), South Australian
44
45
46 324 Department for Health and Wellbeing (reference HREC/18/SAH/90) and New South Wales
47
48
49 325 Population and Health Services (reference 2019/ETH12028) Human Research Ethics
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52 326 Committees.
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23
24
25 335 strategic direction and advice to the ADNeT Registry project.
26
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30 336 **DATA AVAILABILITY STATEMENT**

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34 337 Researchers interested in collaboration are invited to contact the research team to access the
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37 338 data available in ROSA. In addition to the data described here, similar data is available from
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40 339 aged care users without dementia, and state-based hospitalisation data for some Australian
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43 340 states. Data linkage is ongoing and is being updated over time.
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3 **SUPPLEMENTARY MATERIALS**
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5 Supplementary Table 1. The ROSA Dementia Cohort Comprehensive Demographic and Clinical
6 Characteristics

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	<i>n</i> (%)	
	All (<i>n</i> =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 (<i>n</i> =214,780)		
	Has carer	185,118 (86.2)
	No carer	14,781 (6.9)
	Missing	14,836 (6.9)

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		<i>n</i> (%)
		All (<i>n</i> =373,695)
Carer relationship ^b (<i>n</i> =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 (<i>n</i> =185,118)		
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		
	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 (<i>n</i> =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 (<i>n</i> =122,253) (mean, SD)		
Dead at June 30 2016		249.682 (66.8)
Age at death (<i>n</i> =249,682) (mean, SD)		87.5 (6.6)
Years from cohort entry to death (<i>n</i> =249,682) (mean, SD)		2.1 (1.7)
Primary cause of death (<i>n</i> =249,682)		
	Circulatory disease	87,604 (35.1)
	Heart disease	54,412 (21.8)
	Cerebrovascular disease	30,246 (21.1)

		<i>n</i> (%)
		All (<i>n</i> =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