



BMJ Open Registry of Senior Australians (ROSA): integrating cross-sectoral information to evaluate quality and safety of care provided to older people

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ABSTRACT

Purpose The Registry of Senior Australians (ROSA) was established to evaluate aged care experiences in Australia. In this manuscript, we describe the ROSA framework, the two ROSA cohorts, highlights from research findings, and future plans.

Participants The South Australian *ROSA Prospective Cohort* (August 2018–June 2020) enrolled 26 605 participants, of which 59.2% (N=15 745) are women, with a median age of 83 (interquartile range (IQR) 77–88). The National *ROSA Historical Cohort* (January 2002–June 2020) includes 1 694 206 participants with an aged care eligibility assessment, of which 59.1% (N=1 001 705) are women and the median age is 78 (IQR 72–83).

Findings to date Most research using the ROSA has focused on dementia, service accessibility, quality and safety of care, falls and injuries and quality use of medicines. The ROSA has also examined the experience of individuals with highly prevalent and understudied conditions in aged care settings (eg, eye and mental health) and aspects of services (eg, built environment) and innovation (eg, mobile radiological services) that can affect older people's health. Important learnings from the ROSA's development include the significant resources and multidisciplinary expertise required for establishing this platform. Between 2018 and 2022, 43 academic publications, eight reports of the Australian Government Royal Commission into Aged Care Quality and Safety, and several reports to state health authorities and professional societies have used the ROSA.

Future plans Our plans include to: (1) continue delivering high-quality evidence to support the improvement of ageing and aged care services; (2) influence and improve the quality of research in and for the aged care sector; (3) expand scope to facilitate examining aims in more depth; (4) include future aged care sector data collections within the ROSA; (5) inform best practices and innovate how consumer engagement occurs in research; (6) monitor and evaluate the impact of the 2021 Australian Aged Care Reforms.

INTRODUCTION

More than five million older people across 26 countries lived in long-term care (ie, nursing homes or residential aged care facilities

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ High generalisability and coverage: The Registry of Senior Australians (ROSA) Historical Cohort includes individuals accessing any aged care services in Australia and the ROSA Prospective Cohort has full capture of the South Australian individuals having aged care eligibility assessments and subsequent services.
- ⇒ The ROSA platform relies on efficient and pragmatic real-world data collections, which reduces the data collection burden for providers and older people, and creates cross-setting and real-world evidence from individuals normally not be included in clinical trials.
- ⇒ The number of individuals in the ROSA cohorts allows for the examination of infrequent but important events for older people in aged care settings, including sentinel events like premature mortality.
- ⇒ The ROSA platform relies on existing observational data. Internal validity is of concern and only associations are inferred from our analyses.
- ⇒ The ROSA platform has data access delays and lacks information on important areas, including quality of life, consumer experience, in-depth clinical information.

(RACFs)) in 2016.¹ The provision of optimal individualised person-centred care for older people in long-term care facilities and for those living in the community is a recognised long-standing challenge (ie, increasing demands of an ageing population) and is further complicated by emerging challenges (ie, COVID-19).^{1 2} The imperative for active monitoring, surveillance, and evaluation of care provision in aged care to support and inform quality improvement efforts and care planning, has been evident for many years and amplified since COVID-19. Care provision worldwide has changed and health policies to address and adapt to the impact of COVID-19 have been implemented.³

In Australia, where currently 4.2 million people are aged ≥ 65 years⁴ and 1.5 million access aged care services each year,⁵ the monitoring and evaluation of individuals in aged care settings has been a persistent challenge, even prior to the pandemic.² Twenty investigations into quality of care provided to older Australians have occurred in the last 20 years, which included the recent Royal Commission into Aged Care Quality and Safety (2018–2021).⁶ The Australian public's confidence in the aged care and healthcare sectors caring for older people is damaged.² The ability of the Australian aged care sector to promote and demonstrate improvement at a population level is limited due to a lack of existing, coordinated, system performance framework to underpin quality improvement efforts.² While a number of aged care sector reforms are due to be introduced in Australia from 2021 onwards, the effect of these reforms remains to be determined.⁷

In 2017, the Registry of Senior Australians (ROSA) platform was established with support from the South Australian Government.^{8,9} With an initial investment of AUD\$4.2 million over a four year period, the ROSA platform that includes a Prospective and a Historical Cohort was established.^{8,9} Since 2021, the ROSA is supported by the Australian Government Medical Research Future Fund and ROSA partner organisations, which include three aged care providers. Within five years, the ROSA has achieved its goals of creating a unique national resource for powerful analytical evaluation of the characteristics, needs and outcomes of individuals in aged care settings to produce robust evidence for evaluation of access and quality of care, innovations for the aged care sector, monitoring and benchmarking of quality and safety of care in Australia, and has expanded to address the emerging needs of older Australians. This resource has contributed to policy changes in Australia regarding how quality of care is defined and measured.^{10–14} In this manuscript,

we describe the ROSA platform framework, the current cohorts, highlights from research conducted to date and future plans.

COHORT DESCRIPTION

Framework. The ROSA data platform is comprised of two cohorts ([figure 1](#)). This includes a prospectively enrolled cohort in the state of South Australia (approximately 7% of Australia's population) that contains identifiable provider level information, named the Registry of Older South Australians or 'ROSA Prospective' (N=26 600 participants),⁸ and a retrospective national de-identified cohort, named 'ROSA Historical' (N~3.5 million participants).⁹ Both cohorts are built from the linkage of federal and state-based datasets from the aged care, healthcare, and social welfare sectors by a number of agencies through the coordination of the ROSA team ([table 1](#)). The two cohorts are independent and have separate ethics and governance approvals and data for these cohorts are stored in separate Australian government approved secured servers.¹⁵ The core datasets that make up the ROSA Prospective and ROSA Historical are the same and include the Australian Institute of Health and Welfare's National Aged Care Data Clearinghouse and National Death Index, Australian Government's Medicare Benefits Schedule and Pharmaceutical Benefit Scheme datasets, and the state-based hospitalisation, emergency department and ambulance service records ([table 1](#)). The National Aged Care Data Clearinghouse contains the core aged care datasets, which have evolved significantly over the years due to the evolution of federal aged care programmes ([figure 2](#)).

ROSA Prospective Cohort. Established in April 2018,⁸ this dataset contains data for people in South Australia aged ≥ 65 years or ≥ 50 years of Aboriginal or Torres Strait

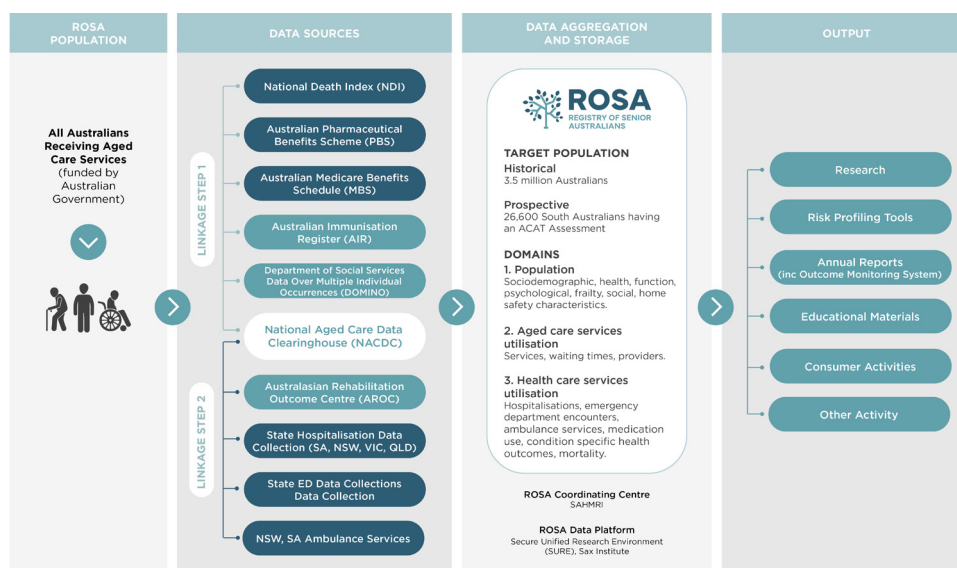


Figure 1 The Registry of Senior Australians platform and framework. ACAT, Aged Care Eligibility Assessment; ED, emergency department; NSW, New South Wales; QLD, Queensland; SAHMRI, South Australian Health and Medical Research Institute; ROSA, Registry of Senior Australians; VIC, Victoria.

Table 1 ROSA data sources, data custodians, and data integrating authorities

Data source	Custodian	Data integrating authority	Included in ROSA cohorts
National Aged Care, Medicare and Mortality Records			
National Aged Care Data Clearinghouse (NACDC) ⁵²	Various	AIHW	Prospective, Historical
Medicare Benefits Schedule (MBS) ⁵³	Department of Health, Australian Government	AIHW	Prospective, Historical
Pharmaceutical Benefits Scheme (PBS) ⁵⁴	Department of Health, Australian Government	AIHW	Prospective, Historical
National Death Index (NDI) ⁵⁵	Registrars of Births, Deaths and Marriages, Australian Government	AIHW	Prospective, Historical
State Admitted Hospitalisation Records			
Integrated SA Activity Collection	SA Health	SA NT DataLink	Prospective, Historical
NSW Admitted Patient Data Collection	NSW Ministry of Health	Centre for Health Record Linkage	Historical
VIC Admitted Episodes Dataset	VIC Health	Centre for Victorian Data Linkage	Historical
QLD Hospital Admitted Patient Data Collection	QLD Health	QLD Health Statistical Services Branch	Historical
State Emergency Department Records			
Emergency Department Data Collection	SA Health	SA NT DataLink	Prospective, Historical
NSW Emergency Department Data Collection	NSW Ministry of Health	Centre for Health Record Linkage	Historical
VIC Emergency Minimum Dataset	VIC Health	Centre for Victorian Data Linkage	Historical
Emergency Department Collection (includes Emergency Department Information System and FirstNet data)	QLD Health	QLD Health Statistical Services Branch	Historical
State Ambulance Records			
SA Ambulance Services Records	SA Ambulance Service/SA Health	SA NT DataLink	Prospective, Historical*
NSW Ambulance-Patient Health Care Record and NSW Electronic Medical Record	NSW Ministry of Health	Centre for Health Record Linkage	Historical
Additional Datasets			
Australian Immunisation Register	Department of Health, Australian Government	AIHW	Historical†
Department of Social Services Data Over Multiple Individual Occurrences (DOMINO)	Department of Social Services, Australian Government	AIHW	Historical*
Australasian Rehabilitation Outcomes Centre (AROC) Dataset	University of Wollongong	AIHW	Historical*

*Data linkage approved; first linkage is anticipated by 2022.
 †Data linkage approved; first linkage is anticipated by 2023 due to data availability.
 AIHW, Australian Institute of Health and Welfare; NSW, New South Wales; QLD, Queensland; SA, South Australia; VIC, Victoria.

Islander background, who have had an aged care eligibility assessment since April 2018. The ROSA Prospective cohort is prospectively enrolled through an opt-out consent process. Participants in this cohort allow for the linkage of subsequent aged care and healthcare data, and access to certain identifiable information (eg,

service providers). Individual identifiers in this cohort are used for data linkage purposes but are not available to researchers. Using the Prospective cohort, reporting to service providers is possible. Between 1 August 2018 and 30 June 2020, 26605 individuals were enrolled in

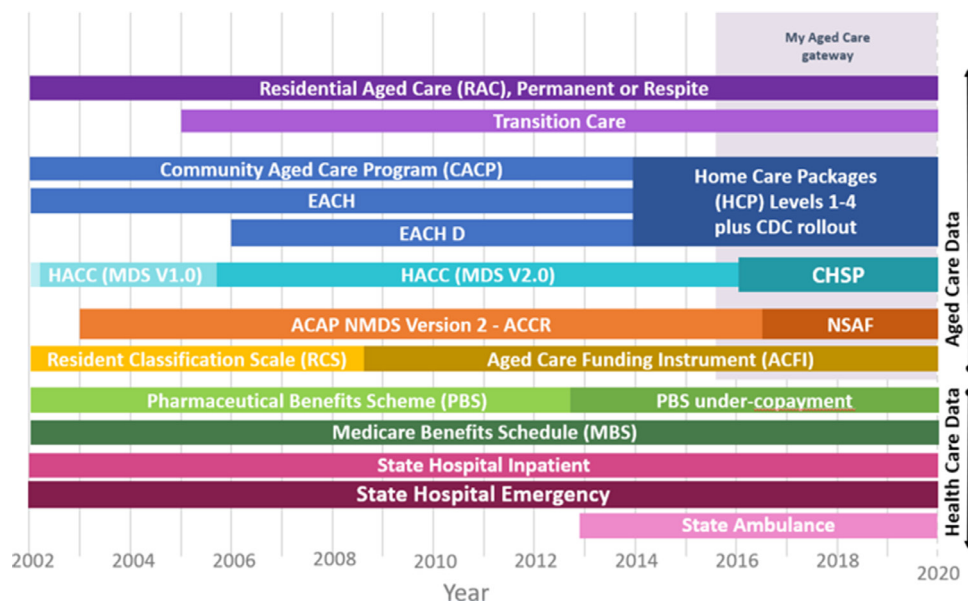


Figure 2 Timeline of aged care programmes and specific datasets captured within the Registry of Senior Australians platform, 2002–2020. ACCR, Aged Care Client Record; ACAP, Aged Care Assessment Programme; CDC, Consumer Directed Care; CHSP, Commonwealth Home Support Programme; EACH, Extended Aged Care at Home; EACH-D, Extended Aged Care at Home–Dementia; HACC, Home and Community Care; MDS, Minimum Data Set; NMDS, National Minimum Data Set; NSAF, National Screening and Assessment Form. Adapted from Khadka *et al.*⁵¹

Prospective ROSA and 1.5% (n=395) of eligible individuals opted-out (table 2).

ROSA Historical Cohort. Established in November 2017 and last updated in December 2021, this cohort is a retrospective, national, de-identified cohort that includes every older person in Australia aged ≥ 65 years or ≥ 50 years for individuals of Aboriginal or Torres Strait Islander background, who have accessed an aged care service or been evaluated for eligibility for aged care services. In its entirety, this cohort contains 3 484 925 million individuals from 1 January 2002 to 30 June 2020, of which 1 694 206 had aged care eligibility assessments, and are at a similar point of entry to the ROSA Prospective cohort, between 1 July 2003 and 30 June 2020 (table 2). The state-based hospital and emergency department data collections included in the Historical Cohort currently include four out of the eight Australian states/major territories—New South Wales, Victoria, Queensland and South Australia—which represent 87% of the cohort accessing aged care services nationally. In 2022, the ROSA Historical Cohort received ethics approval to link data from three additional national data collections including the Australian Immunisation Register, Department of Social Services Data Over Multiple Individuals Occurrence and Australasian Rehabilitation Outcomes Centre Dataset and is due to be linked by 2023.

Patient and public involvement

The ROSA Governance has a Consumer and Community Engagement Advisory Committee, which includes six community representatives and one consumer representative organisation. This Committee provides the ROSA team with consultation, collaboration and oversight into

priority setting, question development, study execution, interpretation of results and research translation. Additionally, two consumers' representatives are part of the ROSA Steering Committee, which oversees ROSA's operations.

FINDINGS TO DATE

Highlights of scientific findings to date

The profile of individuals accessing aged care services either at home with home care packages or at RACFs has changed in the last decade, with individuals generally being older, using more medications, having more health conditions and being frailer in more recent years. For example, for individuals entering RACFs in 2015, the median age was 86 years (interquartile range (IQR) 80–90), median number of medicines dispensed was 10 (IQR 7–14), the proportion of individuals with ≥ 5 comorbid conditions was 62.8%, and 49.7% had a higher frailty index score (≥ 0.3), compared with 84 years (IQR 79–88), median of nine medicines (IQR 6–12), 52.3% with ≥ 5 comorbid conditions and 19.7% with a higher frailty index score (≥ 0.3) in 2006.⁹ We have also found that individuals are reporting more pain (20.2% in 2014 compared with 4.9% in 2005) at the time of aged care eligibility assessments,¹⁶ and more depression when entering care (53.2% in 2016 compared with 41.9% in 2008), while conditions like phobia/anxiety have remained steady¹⁷ and the prevalence of dementia has decreased (46.6% in 2014 compared with 50.0% in 2008).¹⁸

Dementia disproportionately affects older individuals in the aged care sector and the quality of care provided to people with

Table 2 ROSA Prospective and Historical cohort characteristics and aged and healthcare service records

	ROSA Prospective cohort	ROSA Historical cohort	ROSA Historical cohort with ACATs/NSAF
Reporting period	August 2018–June 2020	January 2002–June 2020	July 2003–June 2020
Total individuals, N	26605	3484925	1694206
Women, N (%)*	15745 (59.2)	2049973 (59.0)	1001705 (59.1)
Median age at first activity (IQR), years*†	83 (77–88)	76 (70–82)	78 (72–83)‡
Dementia, N (%)§	5558 (20.9)	NA¶	619466 (36.6)
Median follow-up, (IQR)	362 (207–518) days	5 (1–10) years	6 (2–11) years
Year (first activity)			
<2015	–	2 688 651 (77.2)	1 455 424 (85.9)
2016	–	157 324 (4.5)	62 909 (3.7)
2017	–	183 805 (5.3)	61 947 (3.7)
2018**	7673 (28.8)	173 430 (5.0)	53 632 (3.2)
2019	15 440 (58.0)	195 296 (5.6)	45 198 (2.7)
2020 (up to June 30)††	3492 (13.1)	86 419 (2.5)	15 096 (0.9)
Death‡‡, N (%)	5177 (19.5)	1 786 055 (51.3)	1 148 932 (67.8)
Aged care services accessed§§, N(%)			
Home and community services¶¶	17 313 (65.1)	1 411 558 (83.3)	2 891 067 (83.0)
Home care packages***	4233 (15.9)	457 132 (13.1)	427 710 (25.2)
Respite care	8332 (31.3)	601 292 (17.3)	557 410 (32.9)
Transition care	3414 (12.8)	212 598 (6.1)	210 992 (12.5)
Permanent residential aged care services	6286 (23.6)	1 129 317 (32.4)	902 329 (53.3)
Healthcare services activity†††, N			
Medicare Benefits Schedule records	6 088 262	1 966 510 376	1 095 863 149
Individual services	4 322 058	1 468 721 948	811 460 675
Pharmaceutical Benefits Scheme records	4 741 870	1 892 316 281	1 126 918 649
Individual scripts	4 753 577	1 900 587 221	1 130 724 992

*Missing data: Sex (ROSA Prospective n=52, ROSA National Historical n=11,152, ROSA Historical Cohort with ACAT/NSAF n<5); age (ROSA National Historical n=340).

†Age calculation: ROSA Prospective—age at first ACAT, ROSA Historical—age at first aged care service, ROSA National Historical with ACAT—age at first ACAT.

‡If median age is calculated using the first aged care eligibility assessment as the first activity the median age of the cohort is 82 (IQR 76–87).

§Dementia ascertained from aged care eligibility assessment (Aged Care Assessment Programme or National Screening Assessment Form), entry into care assessment (Aged Care Funding Instrument) and RxRisk-V health conditions.

¶Not available for the entire cohort. Only those with aged care eligibility assessment have dementia diagnoses available.

**Prospective ROSA first participant was in August 2018.

††Data are available in financial years in Australia, most recent data are up to 2019/2020 financial year.

‡‡Mortality at the end of the reporting period (30 June 2020).

§§Individuals who accessed services at any time during the reporting period, not exclusive groups.

¶¶Any type of community-based home care services not part of bundled packages, this includes services part of the Home And Community Care Services and Commonwealth Home Support Programme.

***All types of bundled aged care services at home, this includes services part of the Extended Aged Care at Home Programme, Extended Aged Care at Home-Dementia Programme, Community Aged Care Programme and Home Care Package Programme.

†††Number of records and individual services accessed by, or medications dispensed to, the cohort at any time during the reporting period.

ACAT, Aged Care Eligibility Assessments performed by an Aged Care Assessment Team; IQR, Interquartile Range; NSAF, National Screening and Assessment Form; ROSA, Registry of Senior Australians.

dementia is varied. Individuals in the aged care sector represent almost 40% of the estimated prevalent cases of dementia in Australia.¹⁹ The prevalence of dementia in new users of aged care services ranges from up to 48% for those entering RACFs to 22% for those accessing home care packages (2015 estimates).⁹ The cohort of people with dementia in the ROSA Historical Cohort is largely comparable to cohorts captured in international dementia

registries, demonstrating ROSA's potential to contribute to the examination of the quality of care provided to older people with dementia and facilitating international benchmarks.²⁰ We have used the ROSA dementia cohort to determine that respite services are valuable for these individuals, allowing them to delay entering residential aged care. We have also determined that hip fracture outcomes (ie, mortality, institutionalisation) are worse in

people with dementia, providing insights for service planning for those in aged care settings.²¹ We have described a relatively unchanged quality of care pattern between 2011 and 2016 for older people with dementia, but with significant national variation, measured by quality indicators that include the use of antipsychotics, acetylcholinesterase inhibitor or memantine, experience of high sedative load, incidence of hospitalisations for dementia or delirium and access to services like health assessments or chronic disease management plans.^{22 23}

Not all older people access services they have been approved for and the wait time and type of services they access affects their health. In our examination of 800 000 first-time aged care eligibility assessments in Australia between 2003 and 2013, 82% were approved for permanent residential aged care, 80% for respite, 50% for home care packages and 13% for transition care.²⁴ However, 28% of people did not access any services within one year of approvals.²⁴ We found that a number of factors were associated with the successful uptake of services, including being a woman, dementia status, history of falls, depression and incontinence.

We have determined that waiting more than six months compared with less than 30 days for home care packages (ie, coordinated bundled services to support older people to live at home)²⁵ is associated with a higher risk of mortality and time to entry to residential aged care two years after entering the service.²⁶ This work informed recommendations made by the Royal Commission into Aged Care Quality and Safety in its Interim Report regarding the increase in the availability of home care packages nationally so that older people do not deteriorate while waiting for care.²⁷

In our assessment of aged care services delivering on their intended purpose, we found, for example, that respite care reduced the overall number of days people spend in long-term care.²⁸ Specifically, our study of 480 862 people with approved respite care and 177 596 who accessed care in the first year after approval, found that individuals who use this service as recommended (ie, periodically instead of as an initialisation for permanent residential care) spent less overall days of their lives in RACFs (median 323 days (IQR 159–509) compared with 507 days (IQR 178–676)).²⁸ However, we found that the transition care programme may have limited efficacy and requires further evaluation.²⁹ Of the 121 596 individuals who accessed transition care services between 2007 and 2015, only 38% reported an improvement in their functional independence, more than half were discharged home and only 60% remained home six months after discharge.²⁹

Older people in the aged care sector accessed a significant amount of healthcare services for acute events but less so for preventive and management care. Older people in RACFs often presented to emergency departments (in 2016, 43.5% of home care recipients and 31.5% of RACF residents), experienced unplanned hospitalisations (in 2016, 44.9% of home care recipients and 31.5% of RACF residents), and were frequent users of healthcare services

(97% see a general practitioner each year, 53% see an after hours general practitioner). We have also reported that after entry into RACFs people were less frequently hospitalised than in the year prior.³⁰ However, access to health assessments (31.1% of home care recipients, 45% of RACF residents), or services for managing of complex conditions, including chronic disease management services (11% of home care recipients, 47.1% of RACF residents) is not optimal.⁹

Polypharmacy is common in aged care recipients and use of medicines and services to support quality use of medicines could be improved. Individuals receiving home care packages are on a median of nine medicines and 10 for those living at RACFs.⁹ Almost two-thirds (62.2%) of new RACF residents receive at least one high-risk medicine (as defined by the Institute for Safe Medication Practices) in the year before RACF entry³¹ and antipsychotic use increases after entry to RACF for residents with and without dementia.³² We also have reported that incident antipsychotic use after RACF entry is associated with a higher risk of mortality.³³

Judicious antibiotic use is another key focus in RACFs, given the risk of antibiotic resistance and adverse events associated with unnecessary or inappropriate use. Our examination of national trends in systemic antibiotic use in Australian RACFs identified a 39% relative increase in overall utilisation between 2005–2006 and 2015–2016 (from 67.6 to 93.8 defined daily dose/1000 resident days), with considerable facility-level variation observed.^{34 35} Recent analyses suggest little to no change in the annual national prevalence of antipsychotic, opioid, antibiotic and high sedative load medicines use in Australian RACFs between 2014–2015 and 2018–2019,³⁶ indicating that additional efforts are needed to optimise the use of these medicines.

Despite a high burden of medicines use in this population, and some evidence of benefits in reducing use of certain medicine classes and impact on health, we have found that Home Medicines Reviews and Residential Medication Management Reviews (RMMRs) (ie, comprehensive medicines reviews conducted by pharmacists in collaboration with general practitioner) are underutilised among aged care recipients.⁹ Specifically, we have reported modest changes in the use of six out of 14 medicine classes after an RMMR and a 4.4% lower mortality risk in those who received a RMMR.³⁷ However, only one in five residents received a medication review within three months after entering an RACF and only 3.0% of home care package recipients received a review annually,³⁶ despite recommendations for these services.^{31 38}

The quality of care provided to older Australians in RACFs or at home with home care packages is varied. A set of 12 risk adjusted indicators of quality and safety for residents of RACFs and 15 indicators for recipients of home care packages were developed as part of the ROSA Outcome Monitoring System (OMS).^{36 39} The ROSA OMS includes quality indicators that were considered important, feasible, usable and technically robust and which could influence and drive quality improvement within the aged

care sector. These indicators have been published,^{36 39} and the RACF indicators were extensively used by the Royal Commission into Aged Care Quality and Safety in its investigations to examine quality of care in Australia.^{10–14 40–42} In 2016, for 208 355 long-term residents of 2690 RACFs, we reported a high prevalence of antibiotic use (67.5%), high exposure to high sedative loads (48.1%), 26.8% were exposed to chronic opioid use and 23.5% received an antipsychotic.³⁹ For 90 650 individuals who were recipients of 102 590 home care packages, 38.1% used a chronic disease management plan, 26.4% had an ED presentation and the median wait time for services was 134 (IQR 41–406) days.³⁶ Within the RACFs, at least 15% were outside of the expected range for certain indicators, while for home care packages services, 21% of geographical areas examined had indicators outside of expected ranges.^{36 39} This information is needed for benchmarking purposes to drive quality improvement by the sector.

Highlights of infrastructure and governance learnings to date

Ethics, governance and data access requirements for the development of an integrated aged care, healthcare, and social welfare platform like ROSA are complex and significant resources are needed. The ROSA is supported by two independent research protocols, one for the Prospective Cohort and the other for the Historical Cohort. These protocols required a total of eight individual ethics committee approvals, six downstream ratified ethics approvals, 12 data access and research governance approvals to access 17 data sources from nine data custodians, through five data integrating authorities (table 1). The ethical, governance and administrative complexities surrounding the integration of these existing data sources nationally have also resulted in the ROSA team building significant expertise regarding best approaches for management of such complex linkage processes.

A multi-disciplinary, cross-sectoral and well-integrated team and governance structure were required for the successful delivery of ROSA. The successful development of the ROSA and its research and reporting mechanisms required a core (ie, director, ethics officer, data manager, statistician) and extended (ie, associate director, post-doctoral and senior researchers, statisticians and research support roles) team supported by a sound governance structure. The ROSA Steering Committee provides ROSA with oversight and strategic direction and includes representatives from ten organisations that partner to support and oversee the ROSA activities, as well as consumer/community representatives. Two additional committees, the Consumer and Community Engagement Committee and Aboriginal and Torres Strait Islander Advisory Committee, provide content specific advice and support for the direction of ROSA activities and outputs. Members of ROSA's team have technical expertise in population surveillance, registry science, epidemiology, biostatistics, pharmacoepidemiology and health economics. The team and wider governance structure members also have expertise in the areas that affect older people and the care they need,

and this complements the team's technical capabilities, including: ageing/frailty, geriatrics, aged care/long-term care, quality and safety monitoring, quality use of medicines, aboriginal health, infectious disease, dementia, mental health and health policy. The ROSA governance committee members are based in both the aged care and healthcare sectors, ensuring the cross-sectoral contextualisation of its research and output. Additionally, the ROSA team includes numerous post-doctoral fellows and PhD students to ensure capacity development and mentoring for Australia's future research endeavours in these areas utilising linked population based datasets.

The impact of ROSA findings on aged care policy and practice has already been demonstrated. The ROSA research output and expertise were employed to support the landmark investigations of the Royal Commission into Aged Care Quality and Safety (2018–2021). Several aspects of ROSA's research findings, including work on quality and safety monitoring and psychotropic medicine utilisation and medication reviews, were used by the Royal Commission for its recommendations and are now helping shape and inform subsequent policy initiatives (eg, supporting the expansion of national quality and safety monitoring, increasing home care packages availability, supporting the embedding of pharmacists in RACFs).⁷

Summary. Between 2018 and 2022, 43 academic publications, eight reports of the Royal Commission into Aged Care Quality and Safety,^{10–14 40–42} and several reports to state health authorities and professional societies have used the ROSA platform data. The majority of the ROSA team's research has focused on national priority areas of high burden affecting older people in the aged care sector, including dementia, service accessibility, quality and safety of care, falls and injuries and quality use of medicines.^{9 18 20 21 32 34 36 39 43} Additionally, the ROSA platform has been used to examine the experience of individuals with highly prevalent and often understudied conditions in older people in these settings, for example, eye⁴⁴ and mental health.¹⁷ The ROSA platform has also allowed for the examination of aspects of services (eg, built environment)⁴⁵ and new technology (eg, mobile radiological services)⁴⁶ that can affect older people's health and quality of care received in this setting.

FUTURE PLANS

To continue to deliver high-quality evidence to support improvements directed towards how people age and how aged care services are delivered. The ROSA team will continue to enrol South Australians prospectively and update the National Historical Cohort periodically (every 2 years). Its research will continue to focus on priority areas affecting older people in aged care settings (eg, dementia, primary care in aged care, quality and safety of care). ROSA will continue to provide this evidence to aged care providers, through provider reports (eg, ROSA OMS reports to South Australian providers)³⁹ and to Government entities through commissioned reports.

To influence and improve the quality of research tailored to and produced for the aged care sector. Through the employment of the highest quality analytical approaches, robust and rigorous methodologies, and integrated content area expertise, we will continue to deliver novel, innovative research that aims to understand best practices and how to improve care provision. We are training higher degree students and early career researchers in the development of real-world evidence utilising population-based data platforms.

To expand the scope ROSA's research capabilities. The ROSA team is planning to expand current studies and initiate new studies that examine new data elements soon to be integrated in ROSA from the Australian Immunisation Register, Department of Social Services Data Over Multiple Individual Occurrences and Australasian Rehabilitation Outcomes Registry. This includes, for example, planned research into the patterns of recommended vaccination in older people (eg, influenza, pneumococcal, COVID-19), examination of socio-economic contributions to differences in aged care services access, social determinants of health and well-being in older people, and access to and outcomes of rehabilitation services experienced by those in aged care.

To include future aged care sector data collections within ROSA. The reforms underway in the Australian aged care sector will result in several new data collections, which will benefit from integration within ROSA and expand their utility in terms of generation of high-quality evidence to inform practice and policy. These include the implementation of a new residential aged care funding assessment (Australian National Aged Care Classification, AN-ACC, implemented October 2022),⁴⁷ the redesign of home care, restorative care and respite care service provision into a single Home Support Program (expected July 2023),⁴⁸ and the expansion of the National Quality Indicator Program (expected October 2022).⁴⁹ In addition to these new data collections, the Australian Institute of Health and Welfare has also been charged with the National Aged Care Data Strategy (expected to be launched in 2025), which ultimately hopes to deliver data for the sector resulting in a better understanding of its practices to promote improvements.⁵⁰

To inform best practices and innovate how consumer engagement occurs in health and aged care research. ROSA's Consumer and Community Engagement Strategy 2022–2025 outlines the continuous commitment of ROSA to purposeful engagement with consumers and community in the preparation, execution and translation of its research. This requires incorporating mechanisms for the representation of consumers in activities, providing adequate support for consumer involvement, testing innovative ways to enhance consumer engagement in our research and allocating the necessary funding for the required activities.

To monitor and evaluate the impact of the 2021 Australian Aged Care Reforms. The AUD\$17.7b five pillar reforms announced in May 2021 will impact a number of areas

regarding how care is provided, paid for, accessed and monitored in Australia over the next five years.⁷ ROSA will be a national asset to examine the baseline and longitudinal changes observed as a result of these reforms.

STRENGTHS AND LIMITATIONS

The ROSA Historical Cohort includes individuals accessing any aged care services in Australia. The ROSA Historical Cohort allows for the evaluation of access and health outcomes at the population level and impacts of policy implementation nationally. This highlights the immense value of the ROSA Historical Cohort to evaluate currently planned national aged care reforms. Additionally, the ROSA Prospective Cohort has full capture of the South Australian cohort of people having aged care eligibility assessments and subsequent services and can produce provider reports for the promotion of quality improvement and provision of benchmarks for 240+ South Australian providers. The ROSA platform, for both cohorts, relies on efficient and pragmatic real-world data collections, which reduce the data collection burden for providers and older people and limits potential biases associated with primary data collection in this setting. The ROSA platform creates real-world evidence from individuals included in its linked datasets who normally would not be included in clinical trials. The effectiveness of utilisation of procedures, services and other exposures of interest in often understudied and poorly represented cohorts in clinical trials, can be evaluated using the ROSA platform. Additionally, the well-characterised ROSA Cohorts can be used to examine care provided to older people with conditions that disproportionately affect them, including dementia and osteoporotic fractures. Importantly, the ROSA platform is designed to derive cross-setting information about individuals and its cross-sectoral data allows for the examination of multidimensional aspects of care provision to older people. The number of individuals included in the ROSA Cohorts, especially the ROSA Historical Cohort, also allows for the examination of infrequent but important events, including sentinel events like premature mortality.

The ROSA platform relies on existing observational data. Internal validity is of concern in these types of data and, therefore, a number of safeguards are in place when managing these data, and designing and conducting analyses using the ROSA data. For example, informational bias arising from potentially incorrect or omitted determination of important variables is likely. These occurrences are minimised by deriving variables from multiple sources (eg, assessments and medications are used to ascertain health conditions) and creating or using existing algorithms and indices to ascertain certain variables (eg, quality indicators, comorbidity indices). We also apply validity checks to examine new data supplies (eg, check temporal trends, variation and agreement between various sources). Confounding is addressed through robust analytical techniques (eg, restriction,

multivariable adjustment, propensity scores or other matching approaches) when conducting analyses. Only associations, and not causal relationships, are inferred from our analyses. Other technical limitations of the ROSA platform include: data access delays that can range up to 18+ months from the closure of data collections; data linkage quality for particularly the cohort of people accessing home care services; lack of hospitalisation information for aged care recipients living in Tasmania, Western Australia, Northern Territory and ACT, which represent 13% of the national cohort; limited use of validated tools to measure important geriatric concepts (eg, function, cognitive capacity, frailty); lack of information on quality of life and consumer experience; lack of in-depth clinical information; lack of indication for certain procedures and medications dispensed; and lack of information regarding medication administration.

Other limitations of the ROSA platform, not related to the data itself, include limited accessibility for researchers outside of the ROSA team and costs associated with establishing and maintaining this resource. The use of the datasets contained within ROSA and their data integration is highly regulated by the original data custodians. The use of the data within ROSA is only approved for aims outlined in the existing protocols, multiple institution approvals are required for data access, the workspace used by the project team is restricted and regulated by a data custodian approved authority, and all output resulting from studies requires review and approval by at least one or more data custodians before circulation or dissemination. As previously noted, the ethical, governance and legal reporting requirements of maintaining the ROSA platform require dedicated personnel with intimate knowledge of the policies and regulations surrounding these data access arrangements as well as knowledge of the data collections. The current restrictions do not allow for access to the ROSA platform by external researchers working on independently led research. The data collections that are captured within ROSA have changed over the years and flexibility regarding its access and use are particularly important. Furthermore, significant costs for data acquisition, linkage and storage (on the approved spaces) exist.

COLLABORATIONS

The ROSA team and leadership contain expertise across many disciplines, sectors and settings. At its core, ROSA is built from a partnership of a research institute, three universities, one residential aged care provider, two home care providers, the South Australia state health authority, the state's data integrating authority and a consumer representative organisation. The ROSA Prospective Cohort is also only possible due to the partnership of South Australian Aged Care Assessment Teams, who introduce the Registry to older people. This inter-disciplinary and cross-setting leadership team facilitates the examination of questions affecting older people in aged care

settings, which often requires different perspectives and experience to adequately address.

In addition to its leadership and core team, ROSA has embarked on several collaborative studies with groups that provided content expertise on areas of interest and alignment with ROSA's core goals. Examples of successful areas (and teams) of collaborations include: Aboriginal Health (SAHMRI Wardliparingga Aboriginal Health Equity Theme), National Infection Surveillance Program for Aged Care (University of Melbourne) and Australian Dementia Network (various universities). Additionally, collaborative work with aged care providers, peak bodies, and professional associations has also ensured that ROSA's research is well informed and disseminated to the individuals most involved in the care of older people.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by ROSA Historical Cohort: University of South Australia Human Research Ethics Committee (HREC, Ref: 200489); Australian Institute of Health and Welfare Ethics

Committee (AIHW; Ref: E02018/1/418); South Australian Department for Health and Wellbeing HREC (Ref: HREC/18/SAH/90); New South Wales Population and Health Services Research Ethics Committee (Ref:2019/ETH12028/2019.39); Aboriginal Health Research Ethics Committee (AHREC) in South Australia (Reference: 04-20-895); Aboriginal Health & Medical Research Council of New South Wales (Ref: 1931/22). ROSA Prospective Cohort: South Australian Department for Health and Wellbeing HREC (Ref: HREC/17/SAH/125), AIHW Ethics Committee (Ref: E02018/2/429). Participants gave informed consent to participate in the study before taking part.

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