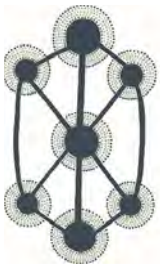


Registry of Older South Australians

The Registry of Older South Australians (ROSA)
South Australian Health and Medical Research Institute
PO Box 11060
Adelaide, South Australia 5001
Ph: +61 8 8128 4662
E: ROSA@sahmri.com

Submission to the Royal Commission into Aged Care Quality and Safety

On behalf of the **Registry of Older South Australians (ROSA, https://rosaresearch.org/),** I (A/Prof Maria Inacio) would like to make a submission to bring to the Commission's attention the significant and timely resource ROSA represents, and how we can contribute to the Royal Commission and the ongoing evaluation, monitoring and improvement of the aged care sector.

ROSA is a powerful cross-sectoral data platform designed to monitor the health, service utilisation, medication use, mortality, and other outcomes of people receiving aged care services in Australia. ROSA's efficient model leverages existing information, bringing together diverse datasets (e.g. Aged Care Assessment Program, Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), Hospitalisation records) collected by organisations throughout the country, to provide us with a full picture of ageing and aged care pathways. Unlike existing silo resources of aged care information, ROSA brought together for the first time nationally both aged care and health care data. ROSA produces evidence to guide decision-making for quality, coordinated, efficient, innovative and age-friendly services and practices.

ROSA has an established National Historical cohort (1997-2017, 2.9 million participants) and is currently collecting data on a South Australian-based Prospective (2018-ongoing, 16,000 participants/year) cohort. The National Historical cohort includes information on the entire population of older people who accessed government-subsidised aged care services in Australia between 1997 and 2017, including 2.1 million aged care assessments, 410,000 home care package uses, 2.2 million entries to residential aged care, 557 MBS encounters and 626 million PBS encounters. For South Australians in both the Historical or Prospective ROSA cohorts, SA Health hospitalisation records will additionally be linked, giving an even more comprehensive view of the interplay between the aged care and health care services being provided to aged care recipients in this state.

ROSA is a resource that allows evidence-driven decision-making to improve the lives of all Australians accessing aged care services. Like other **Australian Clinical Quality Registries**, **ROSA was designed to monitor the effectiveness and appropriateness of care over time, to identify variance and advise on best practices.** In 2018 for example, the ROSA team made contributions to the understanding of the: effect of wait time for aged care services on the health of older Australians,[1] prevalence of dementia in the aged care population and its effect on mortality[2] and increasing pervasiveness of pain in this population.[3] These contributions showcase the unique coverage and ability ROSA has to deliver evidence about this understudied and vulnerable population.

1. *Visvanathan R, et al. Prolonged Wait Time Prior to Entry to Home Care Packages Increases the Risk of Mortality and Transition to Permanent Residential Aged Care Services: Findings from the Registry of Older South Australians (ROSA). Journal of Nutrition Health and Aging. 2019 March; 23(3):217-280.*
2. *Harrison S, et al. Prevalence of dementia and survival with dementia for people accessing aged care services in Australia: trends from 2005-2014. Journal of Gerontology: Medical Sciences. In press March 2019.*
3. *Inacio M, et al. Pain in older Australians Seeking Aged Care Services: Findings from the Registry of Older South Australians (ROSA). Journal of the American Medical Directors Association. In press March 2019.*

ROSA was established in 2017 by the **Healthy Ageing Research Consortium**, a partnership of researchers, clinicians, aged care providers and consumer advocacy groups in South Australia. The

consortium is led by Professor Steve Wesselingh (Executive Director, South Australian Health and Medical Research Institute, SAHMRI), supported by the South Australian Government through the Department for Industry and Skills ($4 million over 4 years) and coordinated under the auspices of the NHMRC accredited SA Academic Health Science and Translation Centre (Health Translation SA). The Consortium's 13 collaborating organisations are: SAHMRI, University of Adelaide, University of South Australia, Flinders University, Helping Hand Inc, Silver Chain Inc, ECH Inc, Adelaide PHN, Country SA PHN, Council on the Ageing SA (COTA SA), Health Consumers Alliance SA, SA NT DataLink, and SA Health. Importantly, the Healthy Ageing Research Consortium and ROSA partner with end-users and consumer advocates to ensure that the research it conducts addresses questions that are relevant to our ageing community, as well as to Government, NGO, Industry and researchers and will provide solutions with real-world impact.

In this document we have outlined how ROSA can contribute to the Royal Commission and the ongoing evaluation, monitoring and improvement of the aged care sector, by specifically focusing on our strengths. These include ROSA's (1) Outcome Monitoring System, our (2) Research, and our (3) Technical Expertise.

1. ROSA's Outcome Monitoring System

ROSA has designed a transparent outcome monitoring and bench-marking system to measure unwarranted variation of care, safety, and quality of services received by individuals obtaining aged care services. This tool is required to efficiently evaluate service systems and support the development of evidence-based quality improvement initiatives.

In brief, this *Outcome Monitoring System* was developed from the synthesis of high-level evidence and recommendations by established Australian or international reporting programs and initiatives. The specific indicators that are included in the current system leverage the linkage between the aged care and health care datasets that exists in ROSA. The specific indicators that ROSA can measure include:

- General safety and quality indicators: including potentially preventable hospitalisations,[1,2] emergency room encounters,[1,2] ambulance service use, falls, fractures,[3] medication related (polypharmacy,[4] potentially inappropriate medications use,[5] hospitalisations), pressure ulcers, delirium and dementia related hospitalisations, weight loss/malnutrition,[6] premature mortality. Wait times for care, changes in activities of daily living needs,[3] use of health assessments (general practitioner, chronic disease management plans, medication reviews, geriatric assessments, **antipsychotic use,**[7] sedative load.
- Disease specific safety and quality indicators: use of cholinesterase-inhibitors or memantine in people with Alzheimer's disease,[7] antimicrobial prescriptions for infection,[8] chronic opioid use for pain.[8]

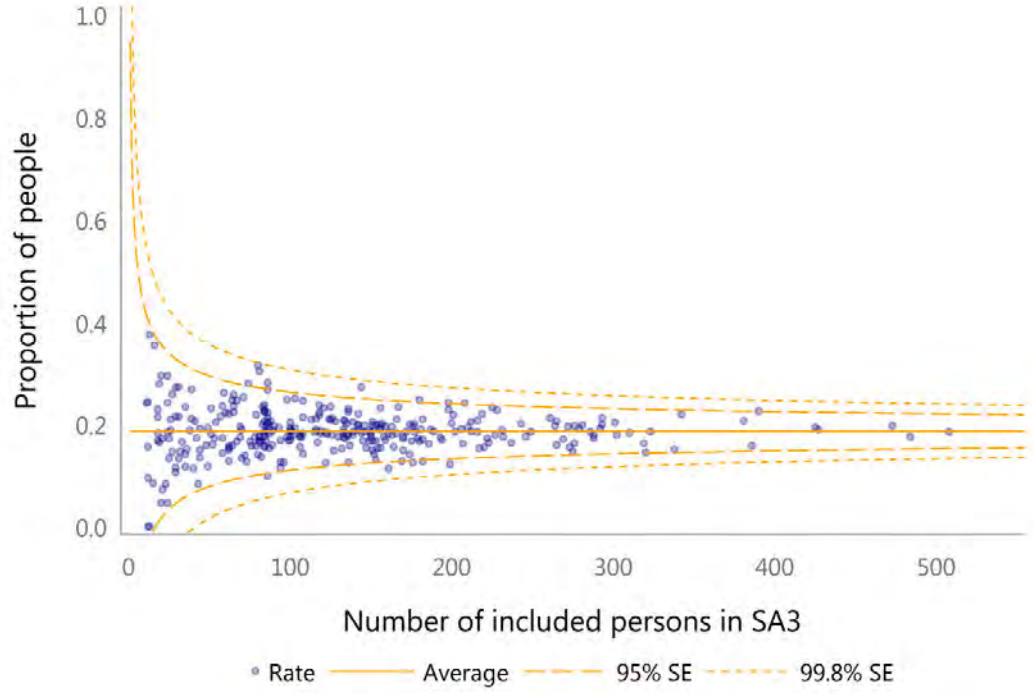
ROSA's *Outcome Monitoring System* provides crude and adjusted rates of specific measures that can be employed to monitor and evaluate unwarranted service variation by geographical area and aged care facility type. The ability to undertake case-mix adjustments (i.e. account for variations in resident characteristics and health history) is an important feature of this system. For the purposes of this submission, an example funnel plot describing variation of rates of antipsychotic medication use by geographical area in Australia based on ROSA data is shown in Figure 1 of this report.

Example (Figure 1): Antipsychotic medication use in residential aged care in Australia in 2016, by geographical area. Historical National ROSA Cohort.

Antipsychotic medication use is major concern in residential care (and in older adults in general) as they can lead to a significant increase in the risk of several adverse events, including falls and death. In the *ROSA Outcome Monitoring System,* we measure the proportion of long-term residents of aged care (live in residential care for more than 100 days) who had **at least 2 prescriptions** of antipsychotic medications within a 6 months period to **conservatively estimate antipsychotic** exposure in this population.

Geographical variation in the use of antipsychotic use can be illustrated using visualisation tools like funnel plots (**Figure 1**). In our example, this funnel plot illustrates the average proportion of people who used antipsychotic medications at specific geographical areas and its upper and lower proportion boundaries (i.e. lines in the graph). Each dot in the graph represents a geographical area and the volume of people in residential care in that area. Figure 1 shows the adjusted rates of antipsychotic medication use, which importantly accounts for differences in the characteristics of the residents of each area. Age, gender, and history of antipsychotic use prior to entry into residential care were accounted for in the analysis. **The average proportion of long-term residents of aged care facilities with at least 2 antipsychotic medication prescriptions within a 6-month period in 2016 was approximately 18%** (95% confidence intervals 18.2-18.9%). This represents appropriately 7,858 out of 42,341 individuals.

Figure 1. Variation in Adjusted Proportion of Long-Term Permanent Residential Aged Care Residents Who Were Exposed to Antipsychotic Medications, 2016



PRAC=Permanent residential aged care. SA3= Australian Bureau of Statistics Statistical Area 3. Only SA3 with >10 residents shown in figure. SE=Standard error.

2. Research

Using the National Historical ROSA cohort data, our research team have published a number of studies, bringing to light issues of interest to the aged care sector. Our early studies have focused on the effect of wait time for home care packages on mortality and entry into residential aged care, prevalence of dementia on people entering the aged care sector and the effect of dementia on mortality, the increasing prevalence of pain in this population, and effectiveness of respite services. Our recent publications on these areas include:

- Visvanathan R, Amare A, Wesselingh S, Hearn R, McKechnie, Mussared J, Inacio M. Prolonged Wait Time Prior to Entry to Home Care Packages Increases the Risk of Mortality and Transition to Permanent Residential Aged Care Services: Findings from the Registry of Older South Australians (ROSA). Journal of Nutrition Health and Aging. 2019 March; 23(3):217-280
  Summary: The effect of wait time for home care packages in Australia, where currently 120,000 people wait for them, was evaluated. We determined that in the longer term, people who waited more than 6 months for home care packages had a higher risk of mortality and transition to residential care.

- Harrison S, Lang C, Whitehead C, Crotty M, Ratcliffe J, Wesselingh S, Inacio M. Prevalence of dementia and survival with dementia for people accessing aged care services in Australia: trends from 2005-2014. Journal of Gerontology: Medical Sciences. In press March 2019.
  Summary: Dementia prevalence among Australians accessing home or long-term care services has declined between 2005 and 2014. Mortality rates for people with and without dementia living in long-term care remained stable over time. The decline in prevalence of dementia for people accessing aged care is critical to future projection estimates and planning services.

- Inacio M, Visvanathan R, Lang C, Amare A, Harrison S, Wesselingh S. Pain in older Australians Seeking Aged Care Services: Findings from the Registry of Older South Australians (ROSA). Journal of the American Medical Directors Association. In press March 2019.
  Summary: The 4.1 fold increase in pain prevalence in Australians seeking aged care between 2005 and 2014 reported in this study is valuable for the planning of future services and highlights the need for pain risk profiling of new aged care recipients, which is critical to target pain management interventions.

- Harrison S, Lang C, Whitehead C, Crotty M, Corlis M, Wesselingh S, Inacio M. Residential respite care use is associated with fewer overall days in residential aged care. Submitted to Journal of the American Medical Directors Association March 2019 and accepted for presentation at the ANZ Geriatrics Society Meeting May 2019.
  Summary: Using residential respite care reduces the number of days people spend in residential care when people return home after using respite care. The findings suggest that using residential respite as intended achieves the goal to help people stay living at home longer.

The ROSA team is also currently working on 20 different analyses and in the next few months ROSA will be publishing several studies, including studies on the:

- **major trends in health conditions, frailty burden, and utilisation of medications and health service in the population in aged care**
- mortality of new users of aged care services compared to the general population
- mental health and musculoskeletal burden in the sector
- trends in the utilisation of services (both in older and younger people)
- barriers to access to care
- inappropriate medication use trends and changes before and after entry into care

- costs associated with long waits for home care packages
- antibiotic utilisation practices in the aged care setting and varitions by facility characteritics.

3. Technical expertise

The Healthy Ageing Research Consortium, which developed ROSA, consists of clinicians, academics, aged care providers, and consumer representatives. These content and technical experts were necessary to undertake the work ROSA has accomplished. This consortium is also supported by a team of 10 researchers with technical and methodological expertise in the areas of registries, monitoring and evaluation, quality improvement tool development, epidemiology, pharmacoepidemiology, statistics, computer science, and health economics. This is a competent team in inferential and predictive analytics, which complement descriptive reporting that can be done by government agencies.

To make inferences about large population level datasets like the ones that make up ROSA and are housed by the Australian Institute of Health and Welfare, appropriate analytical tools must be employed, analytical challenges addressed, and integration of clinical, content, and technical expertise is required. The ROSA team is highly experienced in large scale data visualization techniques to explore complex associations, machine learning techniques for data mining, epidemiology, pharmacoepidemiology, and methods for appropriate statistical analysis of observational study cohorts (e.g. addressing confounding, missing data, competing risks).

For more detail on the Healthy Ageing Research Consortium: https://rosaresearch.org/harc-chief-investigators

For more detail on the ROSA Research team: https://rosaresearch.org/researchteam

References

1. Australian Commission on Safety and Quality in Healthcare. A guide to the potentially preventable hospitalisations indicator in Australia. 2017. (Accessed August 15, 2018, at https://www.safetyandquality.gov.au/wp-content/uploads/2017/03/A-guide-to-the-potentially-preventable-hospitalisations-indicator-in-Australia.pdf.)
2. Centers for Medicare and Medicaid Services. Nursing Home Compare Claims Based Quality Measure Technical Specifications 2018. (Accessed September 16, 2018, at https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/Downloads/Nursing-Home-Compare-Claims-based-Measures-Technical-Specifications.pdf.)
3. MDS 3.0 Quality Measures USER'S MANUAL. Prepared for: The Centers for Medicare & Medicaid Services under Contract No. HHSM500- 2013-13015I (HHSM-500-T0001). . 2016. (Accessed October 2, 2018, at https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/Downloads/MDS-30-QM-Users-Manual-V10.pdf.)
4. Masnoon N, Shakib S, Kalisch-Ellett L, Caughey GE. What is polypharmacy? A systematic review of definitions. BMC Geriatr 2017;17:230.
5. By the American Geriatrics Society Beers Criteria Update Expert P. American Geriatrics Society 2019 Updated AGS Beers Criteria(R) for Potentially Inappropriate Medication Use in Older Adults. J Am Geriatr Soc 2019.
6. Australian Government Department of Health. National Aged Care Quality Indicator Program resource manual for residential aged care facilities. 2016. (Accessed August 15, 2017, at https://agedcare.health.gov.au/ensuring-quality/quality-indicators/national-aged-care-quality-indicator-program-resource-manual-for-residential-aged-care-facilities.)
7. Religa D, Fereshtehnejad SM, Cermakova P, et al. SveDem, the Swedish Dementia Registry - a tool for improving the quality of diagnostics, treatment and care of dementia patients in clinical practice. PLoS One 2015;10:e0116538.
8. Ageing and Aged Care Branch, Victorian Government, Department of Health. Strengthening Care Outcomes for Residents with Evidence (SCORE). Melbourne, Victoria2012.