

SAHMRI Registry Centre

Brief 2025

Introduction

The SAHMRI Registry Centre was established in 2018 to bring together the registry science and operational expertise available among our research community, to ultimately strengthen the Institute's existing role in the registry space and expand our research capacity and training in this area.

The Centre brings together a collaboration of registries, including those based within SAHMRI and member registries based externally. The collaboration includes some of Australia's most significant national registries, bringing together a wealth of experience and knowledge. In doing so the Centre provides for increased quality, efficiency, and cost effectiveness, maximising the value of the contributions and advancements made by member Registries.

SAHMRI's Registry Centre provides an important and rich source of translational and observational research data. Well-designed registries, particularly at the population level, form the 'third pillar' of scientific research in conjunction with clinical trials and laboratory work. The SAHMRI research community believes population-based studies founded by leveraging the information available in registries can represent the most reliable option for identifying the actual 'real-world' effects of interventions, treatments and outcomes in the general population.

The SAHMRI Registry Centre will provide a platform to enhance the enormous value of registry data, supporting the utilisation of other important data sources such trials, surveys, biobank data, administrative data sets, and information systems, through data linkage and research collaborations.

Real-world data

Registries provide real-world data that provides direct information about health care patterns, treatment, and outcomes. This highly valuable data can then be used to directly improve clinical practice and patient outcomes. When used to their full capacity Registries present a significant asset to health departments, clinicians and care providers.

The SAHMRI Registry Centre houses globally recognised national Registries:

- The Registry of Senior Australians (ROSA)
- The Australian and New Zealand Dialysis and Transplant Registry (ANZDATA)

As well as the newly formed Australian Particle Therapy Clinical Quality Registry (ASPIRE) and the Transcatheter Aortic Valve Implantation (TAVI) Registry and has a membership of an additional 16 registries based in South Australia.

SAHMRI's data management and analytical capacity in Registry science is further enhanced by a highly regarded ICT capability in the design of Registry platforms and systems. This puts the South Australian Health Sector in a highly regarded position. Registries are a powerful source of information that in addition to efficient and effective improvement in health care and patient outcomes, are expanded with data linkage programs and clinical trials providing a wealth of information.

Integration

Integrating national clinical quality outcomes data into Australia's health care information systems can systematically drive patient-centred improvements in the quality and value of health care to achieve better patient outcomes. Translating outcome data quickly and efficiently into improved clinical practice and thereby continually improving patient outcomes. A small sample of real-world examples of the impact of these key Registries are provided below.

Purpose

The SAHMRI Registry Centre provides a platform to enhance the enormous value of registry data, supporting the utilisation of other important data sources such as trials, surveys, biobank data, administrative data sets, and information systems, through data linkage and research collaborations.

Aims

- Provide the best resources for registry building capacity
- Lead registry science through collaborative opportunities for our scientists
- Develop strong international and industry collaborations
- Continue to support a shared learning environment within our organisation
- Become a leading national and international registry centre

Governance

A collaborative funding arrangement between South Australian Health and Medical Research Institute (SAHMRI), Australia & New Zealand Dialysis & Transplant Registry (ANZDATA) and the Registry of Senior Australians (ROSA) supported the development of the SAHMRI Registry Centre throughout 2022- 2024.

The Centre is now moving to a model of project delivery through centralised project management using our expertise to expand and enhance best practices in registry science and driving innovation and development across the 20 Centre member registries and the broader CQR Sector when appropriate.

The SAHMRI Registry Centre Executive Group

The Executive Group supports the Strategic Director in the work of the Registry Centre:

- SAHMRI Chief Operating Officer and Director Health Policy Centre at SAHMRI
- Strategic Director SAHMRI Registry Centre
- Director Rosa and Joint Academic Lead of the SAHMRI Registry Centre
- Executive Director ANZDATA and Joint Academic Lead of the SAHMRI Registry Centre.

The SAHMRI Registry Centre Advisory Group

The Advisory Group meets quarterly with the purpose of advising and providing guidance on the work of the SAHMRI Registry Centre, specifically in the achievement of its key goals.

Centre Activities

- Annual Symposium
- Quarterly Workshops
- Statistical Education Forums
- Registry Centre Advisory Group
- Funded projects that support the development of member registries
- Advisory support for a broad range of registry requests and activities
- Collaborative grant funded activities that support the development of registries
- Fee for service work that extends beyond the capacity of the Centre to deliver the required work at no cost.

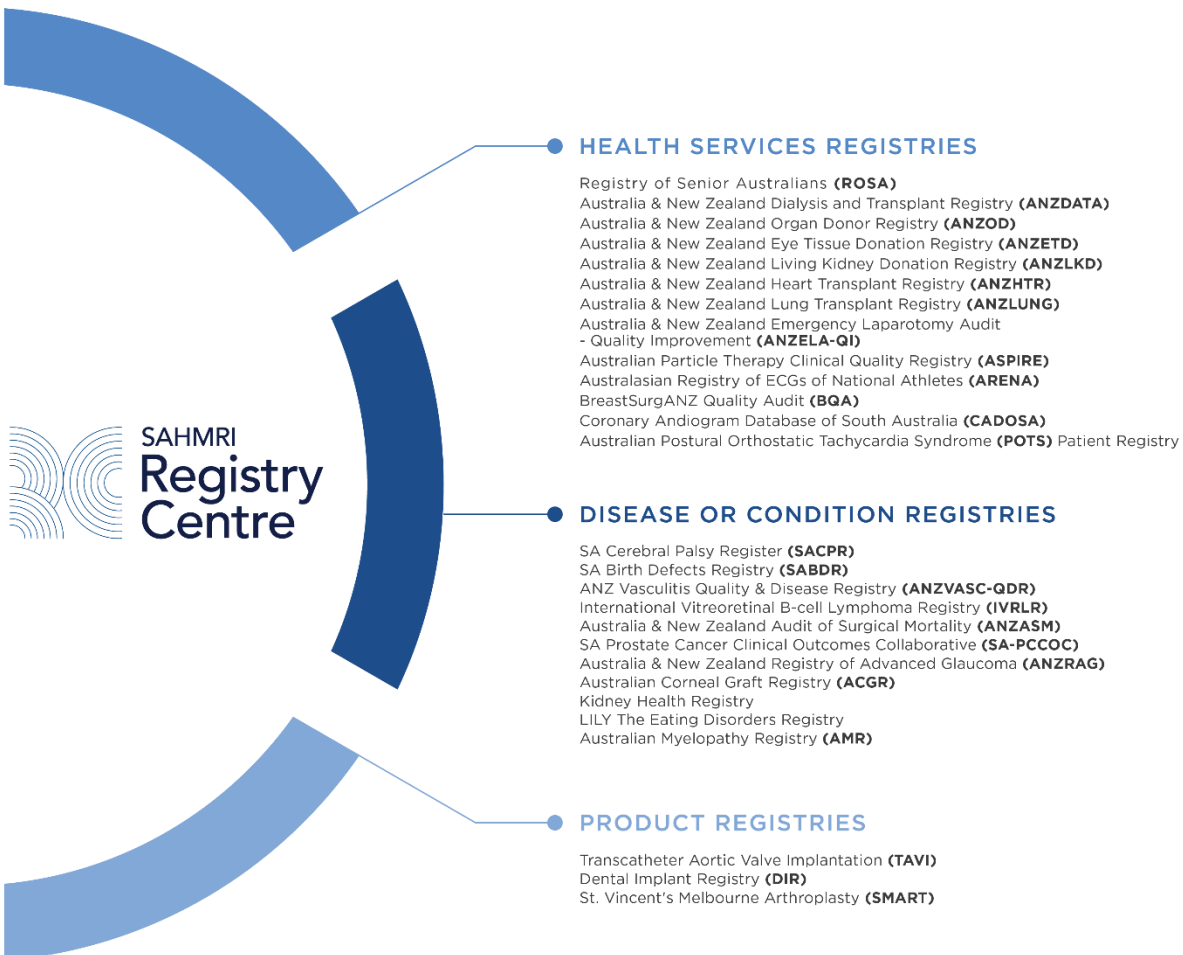
Centralised Project Delivery

The Centre has been funded by the Department of Health Disability and Ageing for the provision of activities that support continued implementation of the National Clinical Quality Registry and Virtual Registry Strategy.

The Centre of excellence for Registries and Registry Science Activities include an initial 18-month work program to cover the below activities:

1. Increasing CQR sector capability in public reporting
2. Piloting a CQR Advisory Service
3. Increasing CQR value and impact case studies and analysis
4. Increasing CQR sector capability in data linkage
5. Consumer Friendly Information

Membership



SUPPORT

Analysis, Reporting, Collaboration, ICT Infrastructure, Data Hosting and Data Management

Note: Some registries are a combination of the above classifications but for the purpose of this diagram registries have been classified by their primary purpose.

Case Studies

The ROSA has improved national understanding of best practices for the aged care sector and created internationally relevant high-quality evidence to improve it. Between 2018 and 2022 ROSA has published **62 peer-reviewed manuscripts, delivered eight (5 led by ROSA) reports for the Australian Government Royal Commission into Aged Care Quality and Safety** and several reports to state health authorities and professional societies. ROSA research has focused on national priorities or high burden areas regarding older people in the aged care sector, including dementia care, service accessibility, quality and safety of care, falls and injuries, and quality use of medicines. Additionally, the ROSA has been used to examine the experience of individuals with high burden of disease, including conditions often understudied in older people in these settings, including eye and mental health.

The ROSA has contributed to policy changes. ROSA's work on quality and safety of care has included the development of a set of twelve risk-adjusted indicators of quality and safety for residents of aged care facilities and fifteen indicators for recipients of home care packages. These quality and safety indicators were extensively used by the Australian Government Royal Commission into Aged Care Quality and Safety in its investigations often as the historical definition of quality of care. [Registry of Senior Australians \(ROSA\) \(rosaresearch.org\)](https://rosaresearch.org)

SAHMRI ICT has proudly supported the software development program for Registries since 2016. It has enhanced its existing core platform for data entry and data management and has added key functionality including an Automated Industry Report System that permits device distributors to request and view custom reports in a self-service manner. SAHMRI currently securely houses data associated with than 1.9 million individual orthopaedic procedures, more 27,000 aged care recipients and over 14,000 dialysis patients and 13,000 transplant patients.

In 2018, SAHMRI ICT created a bespoke automatic electronic data collection system known as RAPID (Real time Automated Platform for Integrated Data capture) to collect patient reported outcomes measures. The RAPID platform also has grown the platform to support Registry-nested clinical trials and studies. RAPID is currently being rolled out to all hospitals undertaking joint replacement procedures in Australia and **SAHMRI currently houses over 3 million individual patient answers from over 70,000 patients.** These data are already being used in various publications to translate clinical information into evidence based best practice care for orthopaedic patients across Australia. <https://sahmri.org.au>

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) is a clinical quality registry that collects and produces a wide range of statistics relating to the outcomes of treatment of those with end stage renal failure. ANZDATA has been in operation since 1977 and **all dialysis and transplant services, in Australia and New Zealand, contribute data to The Registry.** ANZDATA's fundamental purpose is to report on the incidence, prevalence and outcomes of dialysis and transplant treatment for patients with end stage renal disease across Australia and New Zealand.

The Australian and New Zealand Dialysis and Transplant Registry and the Australian and New Zealand Organ Donation registry have a long and successful history. Since the inception of the registries in the early 1960s through the first Annual Report delivered in 1977 to the current extensive evaluations of **more than 35,000 Renal Replacement Therapy patients**, the registries serve both countries exceptionally well.

<https://anzdata.org.au>

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