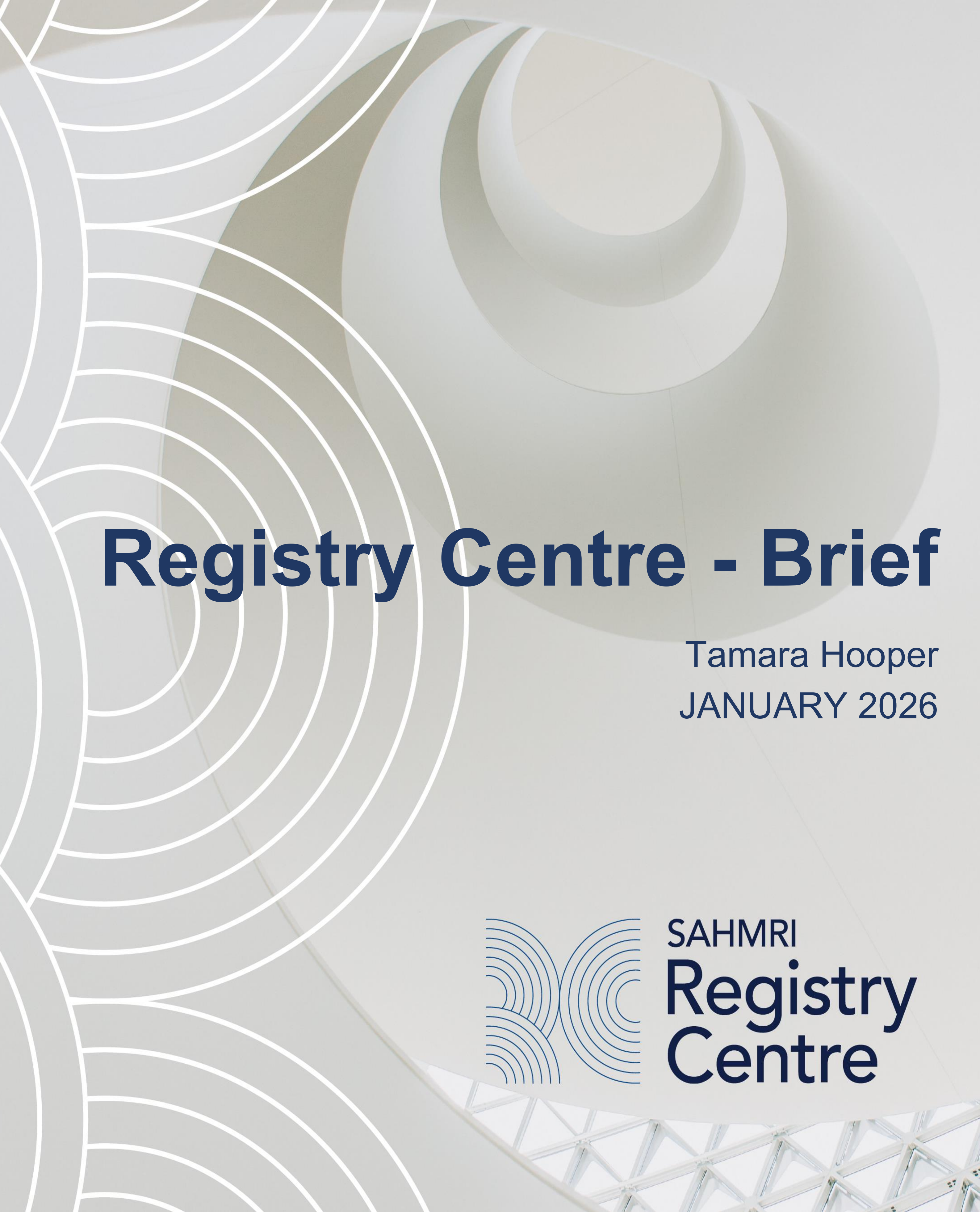

Registry Centre - Brief

Tamara Hooper
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SAHMRI
Registry
Centre

SAHMRI
South Australian Health &
Medical Research Institute

SAHMRI
Registry
Centre

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 provides 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 is a rapidly growing collaboration, consisting of 27 member registries as of 2025. Commencing with mostly South Australian based CQRs, it has expanded to include several major national/bi-national registries, from across the country. Twelve of these are based within SAHMRI including two 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 Australian Transcatheter Valve Therapies (ATVT) Registry.

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.

Purpose

The purpose of the SAHMRI Registry Centre is to 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.

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 27 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

Centralised Project Delivery

This is a fee for service work that extends beyond the capacity of the Registry Centre to deliver the required work at no cost.

- 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 included a program of work from Jan 2024 to June 2025
- Independent Registry Review
- Project management for the establishment of new registries and expansion.

Membership

HEALTH SERVICES REGISTRIES

Registry of Senior Australians **(ROSA)**
Australia & New Zealand Dialysis and Transplant Registry **(ANZDATA)**
Australia & New Zealand Organ Donor Registry **(ANZOD)**
Australia & New Zealand Eye Tissue Donation Registry **(ANZETD)**
Australia & New Zealand Living Kidney Donation Registry **(ANZLKD)**
Australia & New Zealand Heart Transplant Registry **(ANZHTR)**
Australia & New Zealand Lung Transplant Registry **(ANZLUNG)**
Australia & New Zealand Emergency Laparotomy Audit - Quality Improvement **(ANZELA-QI)**
Australian Particle Therapy Clinical Quality Registry **(ASPIRE)**
Australasian Registry of ECGs of National Athletes **(ARENA)**
BreastSurgANZ Quality Audit **(BQA)**
Coronary Angiogram Database of South Australia **(CADOSA)**
Australian Postural Orthostatic Tachycardia Syndrome **(POTS)** Patient Registry

DISEASE OR CONDITION REGISTRIES

SA Cerebral Palsy Register **(SACPR)**
SA Birth Defects Registry **(SABDR)**
ANZ Vasculitis Quality & Disease Registry **(ANZVASC-QDR)**
International Vitreoretinal B-cell Lymphoma Registry **(IVRLR)**
Australia & New Zealand Audit of Surgical Mortality **(ANZASM)**
SA Prostate Cancer Clinical Outcomes Collaborative **(SA-PCCOC)**
Australia & New Zealand Registry of Advanced Glaucoma **(ANZRAG)**
Australian Corneal Graft Registry **(ACGR)**
Kidney Health Registry
LILY The Eating Disorders Registry
MYelopathy NAtural History **(MYNAH)** Registry

PRODUCT REGISTRIES

Australian Transcatheter Valve Therapies Registry **(ATVT)**
Dental Implant Registry **(DIR)**
St. Vincent's Melbourne Arthroplasty **(SMART)**

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.

Contact details

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SAHMRI

Creating Healthier Futures

SAHMRI exists to help people lead healthier lives. South Australia's flagship

not-for-profit health and medical research institute is driven by research excellence that delivers rapid improvements in the prevention, diagnosis, and treatment

of disease.

This is achieved through four health themes – Aboriginal Health Equity, Women and Kids, Precision Cancer Medicine and Lifelong Health.

Home to a leading Aboriginal and Torres Strait Islander research unit, the Wardliparingga Aboriginal health research team is focused on achieving equitable outcomes by responding to community priorities, reflecting our commitment to improving the health and wellbeing of Indigenous communities, which is vital for a healthier future for all.

Designed for collaboration, our landmark building is at the heart of South Australia's Biomedical ecosystem, uniting hospitals, universities and research entities in interdisciplinary partnerships.

Located in the agile, 20-minute city of Adelaide, SAHMRI is embedded in the state's creative, legal and government precincts, inspiring innovation and accelerating the speed to market of discoveries.

Cost effectiveness combined with Australia's R&D tax incentives make SAHMRI a preferred partner for international collaborations.

Our translational impact is profound and growing. We've influenced health policies such as laws on vaping, established a centre of excellence for registries to house health-advancing data, discovered lifesaving therapies such as a treatment for Chronic Myeloid Leukaemia, and developed the evidence-based Omega-3 test and treat program to help prevent preterm births.

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