SAHMRI
South Australian Health &
Medical Research Institute

SAHMRI
Registry
Centre

Annual Report 2025

Letter from the Deputy Director, SAHMRI

The SAHMRI Registry Centre is a recognised centre of excellence, supported by extensive national networks and specialised expertise. The Centre continues to grow as a collaborative national platform and, as of 2025, comprises 27 member registries. During the year, three new registries joined the collaboration: the St Vincent's Melbourne Arthroplasty (SMART) Registry, the MYelopathy NAtural History (MYNAH) Registry, and the Postural Orthostatic Tachycardia Syndrome (POTS) Registry. While initially the Centre consisted of South Australia based clinical quality registries (CQRs), it now includes several major national and bi-national registries, with twelve registries based within SAHMRI.

The Centre is a key contributor to the national effort to enable a more data-driven healthcare system that improves the safety, effectiveness, and appropriateness of care. It continues to support, advocate, collaborate, communicate, educate, and connect across the registry sector, while facilitating the collection, analysis, and application of high-quality data on disease, treatments, and outcomes.

Looking ahead, the Centre has identified an increase in demand across several areas of the CQR sector, including digitisation, integration with electronic medical records, governance and ethics, consistency across jurisdictions, and infrastructure capacity. Addressing these priorities will require continued growth in registry capability and outputs, as well as targeted efforts to improve interoperability across national systems and data assets. Demonstrating the value and impact of CQRs remains critical to their long-term success and recognition within the health system. The Centre contends that integrated impact assessment and coordinated dissemination of successful practices across disciplines and jurisdictions have the potential to significantly amplify the benefits delivered by registries.

During the reporting period, the Registry Centre Project Team successfully completed the Centre of Excellence projects and the Consumer-Friendly Information (CoFI) project. Resources developed through these initiatives, funded by the National Clinical Quality Registry Program, *Australian Government Department of Health, Disability and Ageing*, are publicly available (refer to page 8).

Finally, on behalf of the Executive Group (Professor Maria Inacio and Professor Stephen McDonald) I would like to formally acknowledge and thank Cindy Turner, who retired during the year after ten years of service to the Clinical Quality Registry sector. Her leadership and dedication were instrumental in strengthening the profile and impact of the SAHMRI Registry Centre. In July 2025, Senior Project Manager Tamara Hooper was appointed to the role of Strategic Director and was subsequently appointed Co-Chair of the *Australian Clinical Trials Alliance (ACTA) Clinical Quality Registry Special Interest Group (CQR SIG)*, further enhancing the Centre's national leadership role. Tamara is supported by Project Officer Jennifer Singh, who joined the Registry Centre team in August 2025.

With its growing expertise and national reach, the SAHMRI Registry Centre is well placed to advance registry science, drive innovation and excellence, and deliver meaningful improvements in healthcare, an endeavour I am excited to support.

Professor Caroline Miller

Deputy Director SAHMRI | Executive Lead SAHMRI Registry Centre

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Letter from the Strategic Director, SAHMRI Registry Centre

I am pleased to present the fourth Annual Report of the SAHMRI Registry Centre. The year 2025 was characterised by growth, change, and the successful completion of several major initiatives. Having commenced in my new role in July 2025, I would like to sincerely thank Cindy Turner for her mentorship and continued support, and to wish her every success in her retirement.

Throughout 2025, the SAHMRI Registry Centre continued to strengthen its national profile and collaborative network and welcomed three new registries into its membership. The year also saw significant staff transitions, the completion of Australian Government funded Centre of Excellence and Consumer-Friendly Information (CoFI) projects, and in September 2025 the release of a suite of new national resources (guidance materials, fact sheets, impact case studies, and project reports), supported through the National Clinical Quality Registry Program, administered by the *Australian Government Department of Health, Disability and Ageing*.

Engagement across the sector continued to grow, highlighted by the successful delivery of the inaugural SAHMRI Registry Centre Datathon and an oversubscribed Annual Scientific Symposium. The Centre was also featured in the official launch of CSIRO Publishing's *ConnectSci* website, contributing the feature article Driving safe, smarter healthcare with SAHMRI-Registry Centre, which showcased the Centre's leadership and impact within the CQR landscape.

Representing the SAHMRI Registry Centre, its members, and the broader sector, I was appointed Co-Chair of the *Australian Clinical Trials Alliance* (ACTA) *Clinical Quality Registry Special Interest Group* (CQR SIG), alongside Jade Curtis. I would like to sincerely acknowledge Professor Susannah Ahern and Professor Stephen McDonald, the outgoing Co-Chairs, for their leadership and pivotal contributions in establishing and shaping the ACTA CQR SIG. During the year, three Registry Centre member registries were appointed to the ACTA CQR SIG Executive Committee: the Australian Particle Therapy Clinical Quality Registry (ASPIRE), the South Australian Prostate Cancer Clinical Outcomes Collaboration (SA-PCCOC), and the Australian and New Zealand Audit of Surgical Mortality (ANZASM) Registry.

The Registry Centre also played a leading role in the ACTA Clinical Trials and Registries *Driving Change* Symposium held in November 2025, contributing presentations and workshops that showcased national registry resources and emerging best practice.

Planning is well underway for the 2026 SAHMRI Registry Centre Annual Symposium and Datathon to be held on 12–13th March 2026 in the SAHMRI Auditorium, under the theme *Advancing Equity Through Clinical Quality Registries*. These events will continue to support collaboration, innovation, and leadership across the clinical quality registry sector.

Looking ahead to 2026, I am excited to continue working with and supporting the registry sector as it advances registry science, promotes best practice, and drives meaningful improvements in patient care. Registries can build on past achievements, foster national collaboration, and contribute to a safer, more effective, and data-driven healthcare system by articulating a clear purpose, strengthening engagement with stakeholders, measuring and integrating their impact, and actively communicating the value they provide.

Tamara Hooper

Strategic Director, SAHMRI Registry Centre

Introduction

Purpose

The South Australian Health & Medical Research Institute (SAHMRI) Registry Centre plays a pivotal role in elevating the quality of care and health outcomes for Australians by uniting 27 significant registries nationally, representing 20 per cent of the sector.

With a goal to support, advocate, collaborate, communicate, educate and connect, the SAHMRI Registry Centre facilitates the collection, analysis and application of data on disease, treatments and outcomes.

The Centre provides actionable real-world information that contributes to integrating national clinical quality outcome data into Australia's health care information systems, systematically driving better decisions, safe and high-quality health services and improved patient care.

Aims

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

Governance

The Registry Centre is supported by its Executive Group and Advisory Group.

SAHMRI Registry Centre Executive Group

The Executive Group supports the Strategic Director as a small group to respond to day-to-day activities:

- Professor Caroline Miller – Deputy Director SAHMRI
- Tamara Hooper, Strategic Director SAHMRI Registry Centre
- Professor Maria Inacio – Director ROSA and Joint Academic Lead of the SAHMRI Registry Centre
- Professor Stephen McDonald - Executive Director ANZORRG and Joint Academic Lead of the SAHMRI Registry Centre.

SAHMRI Registry Centre Advisory Group

The Advisory Group, with representation from each member registry, provides advice and guidance on Registry Centre activities and supports the centre in achieving its aims.

Advisory Group Members

SAHMRI	Prof Caroline Miller
SAHMRI Registry Centre	Ms Tamara Hooper
ROSA	A/Prof Maria Inacio A/Prof Gill Caughey
ANZORRG (ANZDATA, ANZOD, ANZLKD, ANZETD, ANZHTR, ANZLUNG)	Prof Stephen McDonald Ms Kelly Marshall
ASPIRE	Ms Kelly Skelton
ANZASM	
ANZELA-QI	Dr Helena Kopunic
BQA	
ACGR	Prof Keryn Williams Dr Miriam Keane
ATVT Registry	Ms Michelle Lorimer Ms Anita Deakin
SABDR, SACPR	Dr Catherine Gibson Ms Heather Scott
SA-PCCOC	Dr Michael O'Callaghan
DIR	Dr Steve Soukoulis
ANZRAG	Ms Karen Hall Ms Bronwyn Usher
IVRLR	Prof Justine Smith
ARENA	A/Prof Jessica Orchard
ANZVASC-QDR	Prof Richard Kitching
Kidney Health Registry	Dr Jordan Li Dr Sarah Bodda
LILY – Eating Disorder	Dr Patrick Russell
CADOSA	A /Prof Rosanna Tavella
MYNAH	Prof Ashish Diwan Dr Nashwa Najib
POTS	Dr Marie-Claire Seeley
SMART	Prof Michelle Dowsey

**Representatives may change throughout the year*

Registry Centre Activities

Events

2026 Registry Centre Annual Scientific Symposium

This year's theme is ***Advancing Equity Through Clinical Quality Registries*** to be held on Friday 13th March 2026.


SAHMRI REGISTRY CENTRE
Annual Symposium
Advancing Equity Through Clinical Quality Registries

We are delighted to have the following speakers confirmed:

- Professor Michael Kidd AO, Australian Chief Medical Officer
- A/Professor Courtney Ryder, Flinders University
- Mary Ann Baquero Geronimo, CEO Federation of Ethnic Communities' Councils of Australia (FECCA)

2026 Registry Centre Datathon

Based on the feedback and success of the 2025 Inaugural Datathon the Centre will host its second Datathon on Thursday 12th March 2026. The Datathon is a collaboration with the Australia and New Zealand Intensive Care Society (ANZICS) CORE Registry, the Australian & New Zealand Dialysis and Transplant Registry (ANZDATA), Australia and New Zealand Hip Fracture Registry (ANZHFR) and the Registry of Senior Australians (ROSA).

2025 Annual Scientific Symposium

The Registry Centre held its 2025 Annual Scientific Symposium on 20 March, a sell-out event with 125 attendees a 16% increase from 2024.

Keynote and plenary speakers included Professor Anne Duggan, CEO of the Australian Commission on Safety and Quality in Health Care, on *Health care variation, clinical quality registries and using data to drive improvement*, and Professor Ginny Barbour, Editor-in-Chief of the *Medical Journal of Australia*, on *The key role of reporting and publication of funding of variation in clinical outcomes*.

The Symposium received positive feedback, with attendees highlighting the breadth of speakers and topics, as well as the engaging panel debate. More details are available in the 2025 SAHMRI Symposium Report.

2025 Inaugural Datathon

On 19 March 2025, the Registry Centre held its inaugural Datathon, bringing together 54 participants, including data scientists, statisticians, data managers, clinicians, and researchers to work with deidentified datasets from sources such as ANZDATA and ANZICS to answer a clinical question. Supported by mentors, judges, and facilitators, teams presented their findings at the end of the day, with the highest-scoring team invited to present at the Symposium the following day. Feedback highlighted the event as interactive, engaging, and a valuable opportunity for networking and collaboration.

Seminar: CQRs within the AIHW National Health Data Hub

On the 9th of April 2025 the SAHMRI Registry Centre held a seminar to investigate what is the AIHW National Health Data Hub and how CQRs fit into the picture. Three speakers included Miriam Lum On, the head of the Integration Development Unit, Data Governance and Integration Group, AIHW and two registry representatives, Shaila Chavan (ANZICS) and Dominique Cadilhac (AuSCR).

Statistical Education Forums

There were six biostatistical research presentations at the SAHMRI Statistics Education Forum in 2025 with attendance averaging 19 participants across the sessions. As well as interesting and useful topics, these forums provide connections to others working in the registry science sector. These sessions are open to anyone in the statistics and analytics workforce. We would like to acknowledge the commitment of Dr Chris Davies from ANZDATA in the coordination of these important knowledge sharing forums. If you or anyone in your team is interested in joining other statisticians and like-minded professionals, please send your details to the Centre via email: *registrycentre@sahmri.com*

2025 ACTA Workshop From the Ground Up

The SAHMRI Registry Centre hosted a workshop at the ACTA 2025 Clinical Trials and Registries Symposium in Melbourne on the18th November.

The session, *From the Ground Up: A Registry Workshop*, provided guidance on establishing a Clinical Quality Registry (CQR), based on the Centre's 10 Steps to establish a Clinical Quality Registry fact sheet.

Facilitated by Helena Kopunic (RACS), Kelly Skelton (ASPIRE), Tamara Hooper, and Jennifer Singh (SAHMRI Registry Centre), the workshop combined practical guidance with an engaging Harry Potter-themed approach, making the content both informative and enjoyable for participants.

Kelly Skelton & Tamara Hooper

Publications

Wade K. *Driving safe, smarter healthcare with SAHMRI-Registry Centre* Nov 2025; SAHMRI Registry Centre feature article as part of the official launch of the CSIRO publishing ConnectSci website

Projects

Centre of Excellence and Consumer-Friendly Information

In September 2025, the National Clinical Quality Registry Program, administered by the *Australian Government Department of Health, Disability and Ageing*, in collaboration with the SAHMRI Registry Centre released a suite of resources to support the CQR sector. To access the documents listed below go to National CQR Program – Best practice materials

Guidance materials

- A Registry Guide to Co-Designing Consumer Friendly Resources
- A Guide to Demonstrating Clinical Quality Registry Impact
- Clinical Quality Registry (CQR) Framework Assessment Tool Reporting

Fact sheets

- 10 Steps to establish a Clinical Quality Registry
- Registry Establishment Cost Drivers
- Clinical Quality Registry (CQR) Establishment Feasibility

Impact case studies

Clinical Quality Registries (CQRs) Collated Impact Case Studies a collection of case studies and impact statements that showcase the diverse impact delivered by SAHMRI Registry Centre member registries

Reports

Available on the SAHMRI Registry Centre website are the full reports for each of the projects

- CQR Advisory Service Pilot Project Report
- CQR Value and Impact Project Report
- Public Reporting Project Report
- Consumer Friendly Information – CoFI Pilot Project Report

Consumer-Friendly Information (CoFI)

Engaging Consumers Material developed in partnership with the Registry for Senior Australians (ROSA), The Australian Corneal Graft Registry (ACGR), and the Transcatheter Aortic Valve Implantation (TAVI) Registry.

Registry Highlights

SAHMRI Registry Centre

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.

HEALTH SERVICES REGISTRIES

Registry of Senior Australians **(ROSA)**
Australia & New Zealand Dialysis and Transplant Registry **(ANZDATA)**
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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

Registry of Senior Australians (ROSA)

The Registry of Senior Australians (ROSA) was founded in 2017 to deliver evidence to improve the quality of ageing and aged care services delivered to older people in Australia. In July 2024, ROSA Research Centre established a partnership between SAHMRI and the Caring Futures Institute within Flinders University's College of Nursing and Health Sciences. The ROSA Research Centre maintains an Australian Clinical Quality Registry and national data platform to conduct innovative and translational research, aimed at understanding and improving the health, service utilisation, medication use, mortality, and other important outcomes of older people.

2025 highlights

Outputs

Publication of 28 academic articles, delivery of four academic, policy and aged care practice-related reports, development of 311 reports for aged care providers in South Australia (214 for residential aged care facilities and 9 for home care services) and delivery of 24 conference presentations (visit this link for a full list).

National aged care programs development:

The ROSA team was involved in the National Aged Care Quality Indicator Program residential care expansion and home care pilot. These programs are key to promoting and supporting transparency, quality improvement, and excellence in care delivery within the aged care sector. In collaboration with HealthConsult and the University of Queensland new staffing quality indicators for enrolled nurses, allied health professionals, and lifestyle officers for residential care were piloted and recommended, which were added to the program in 2025 (visit this link for further information). The home care pilot was finalised, and the indicators are being considered for future implementation in the Support at Home Program rolled out nationally in November 2025 (visit this link for further information). These are examples of contributions and rapid translation of evidence into aged care policy.

Completion of the four-year MRFF project ***'Using big data to create evidence-based primary health care service delivery and policy for the Australian aged care sector'***. This collaborative project between the South Australian Health and Medical Research Institute, Flinders University, University of Adelaide, University of South Australia, SA Dental, ECH Inc., and Silverchain was the winner of the 2025 Future of Aging Awards in the research category. This project delivered critical national evidence into optimal primary care service utilisation, unwarranted variation of care, and what primary care services most affect critical outcomes for those in aged care settings.

Release of the Australian Consortium for Aged Care Australian Consortium for Aged Care (ACAC) Quality Indicator Repository. This resource, which to dates includes more than 6000 measures, is designed for researchers, health and aged care providers, governments, and families of older Australians to access and understand measures that can support and track care quality and support evaluations, reforms and service-level quality improvement initiatives.

ROSA data platform update

ROSA Prospective Cohort (SA only): Using data updates from 2018-2023 for 66,400 aged care recipients in SA, our 2025 release of direct-to-provider ROSA Outcome Monitoring System reports. The next annual cohort update will be received in early 2026.

ROSA Historic National Cohort

Includes ~3.85 million Australians who have accessed an aged care service or been evaluated for eligibility for aged care services (2002-2022). Additional data updates received in September 2025 included linked Australasian Rehabilitation Outcomes Centre (AROC) data.

Australia and New Zealand Organ Replacement Registries Group (ANZORRG)

Launch of ANZORRG

2025 marked an important milestone in the evolution of our registry operations with the introduction of the Australia and New Zealand Organ Replacement Therapies Registry Group (ANZORRG).

For almost five decades, ANZDATA has been recognised as a trusted source of high-quality data and analysis supporting improvements in dialysis and kidney transplant care across Australia and New Zealand. Over time, this capability has grown well beyond renal care, expanding to support a broader suite of organ replacement and donation registries, each contributing to improved clinical understanding, service planning and patient outcomes.

The introduction of the ANZORRG identity in 2025 reflected the growth of our group and the increasingly integrated nature of our work. Rather than representing a change in direction, ANZORRG provides a clearer way to describe the operational group that underpins our multiple bi-national registries, bringing together shared expertise in data collection, analysis and reporting.

Bringing our work together under the ANZORRG banner has strengthened the way we operate across registries, enabling greater consistency in operational oversight, data management, reporting and collaboration. It has also helped articulate the shared infrastructure and expertise that supports each registry, while creating a stronger foundation for future registry-based research and national reporting.

This change has brought alignment and clarity. The day-to-day operations, leadership and identities of individual registries have remained unchanged, with each continuing to operate with the same clinical focus, governance, partnerships and purpose. To support this, ANZORRG launched a new website providing a single, accessible entry point to the group's registries, shared capabilities and framework.

The ANZORRG name has provided a unifying framework that better reflects the breadth of work already underway and positions the group to continue supporting high-quality, data-driven improvements in organ replacement therapies into the future.

Australia & New Zealand Dialysis & Transplant Registry (ANZDATA)

Key Achievements in 2025

ANZDATA Special Report Series Release and Impact

The ANZSN/ANZDATA Special Report: Unit Survey 2024 released in 2025 provided one of the most detailed binational views to date of workforce capacity and haemodialysis service constraints experienced by adult and paediatric kidney units across Australia and Aotearoa New Zealand.

Based on survey responses from nephrology units, the report found significant variation in staffing, with kidney specialists managing an average of 84 patients on kidney replacement therapy and highlighted that two-thirds of Australian units and 80% of New Zealand units are unable to provide haemodialysis at a patient's preferred location due to infrastructure and funding shortfalls. Over half of units reported implementing restrictive measures such as reduced dialysis hours, delayed initiation of treatment, incremental dialysis (fewer than three sessions per week), or prioritisation of home-based therapies in response to capacity pressures.

The report's release stimulated important sector and media engagement, reinforcing its value beyond the registry community. Coverage in clinical media highlighted that insufficient haemodialysis capacity was "harming patients". Clinicians quoted in coverage emphasised that the granularity of the data allows meaningful benchmarking and supports advocacy for infrastructure and workforce investment, and that the evidence base helps clarify service gaps for health planners and governments.

The **combined ANZDATA and ANZSN commentary** that accompanied the report emphasised the report's importance in guiding targeted advocacy with state and federal health ministers, clearly outlining the urgent need to address workforce and infrastructure constraints in kidney services across Australia and Aotearoa New Zealand. A further report on Dialysis Capacity is due for publication later this year. Access the Special Report, accompanying infographic, and ANZDATA/ANZSN commentary.

Development of the KiWI (Kidney Waitlist Index) Score

For many patients, kidney transplant is the optimal treatment for advanced kidney failure and is the most cost-effective treatment modality. Prior to 2013 patients with end stage kidney disease were assessed for suitability onto the kidney transplant waitlist after assessment by kidney transplant physicians and surgeons. While there were criteria for suitability there was no formal or uniform co-morbidity assessment. This led to concerns regarding transparency and equity of criteria for listing throughout Aotearoa New Zealand.

Dr Phil Clayton and Dr Georgie Irish, Executives of ANZDATA and Transplant Epidemiology Group (TrEG) worked closely with New Zealand Transplant Nephrologist Professor Helen Pilmore in a major initiative to improve equity and transparency in kidney transplant waitlisting in Aotearoa New Zealand. Using ANZDATA's comprehensive patient data, they developed the Kidney Waitlist Index (KiWI) score, a robust, evidence-based tool designed specifically for New Zealand patients.

The project involved rigorous statistical modelling, validation, and clinical testing to ensure accuracy and applicability. The score was rigorously derived, validated, and tested in a New Zealand population, and a clinical app was created to support its use in practice. This score has significantly improved performance compared to the New Zealand Survival Score and is now being used as a key tool for transplant suitability in Aotearoa New Zealand. View the KiWI score.

Australia Day Honours

Each year the Australia Day Honours list recognises and celebrates individuals who have made a significant contribution through sustained service, leadership and impact.

Professor Stephen McDonald was appointed a Member of the Order of Australia in recognition of his service to kidney medicine as a clinician, researcher and administrator. Wearing many hats across clinical care, research and health system leadership, his long-standing contribution to ANZDATA has been particularly influential. Beginning his involvement as the Registry's inaugural Clinical Epidemiology Fellow, he went on to lead ANZDATA as Executive Officer, shaping its evolution into a trusted national and international clinical quality registry. Under his leadership, ANZDATA evidence has informed policy, improved access to dialysis and transplantation, and strengthened equity of care, particularly for Aboriginal and Torres Strait Islander peoples and those living in regional and remote communities.

National CQR Capacity Building Grant: PROMs Module Development

In 2025, ANZDATA secured funding through the National Clinical Quality Registries (CQR) Program to develop and pilot a Patient-Reported Outcome Measures (PROMs) module for integration into the registry. This initiative aims to embed patient-reported outcomes into routine data collection, supporting clinicians to better understand patient experiences and deliver more personalised care.

Throughout the year, the project team worked closely with stakeholders to identify priority PROMs, determine collection parameters such as frequency, and establish preferred reporting formats. These consultations ensured the module aligns with both clinical requirements and patient needs.

The PROMs module has been designed and rigorously tested and will be piloted across kidney units in Australia in the coming year. Feedback from this pilot will inform refinements before the module becomes a standard component of ANZDATA reporting, strengthening patient-centred care and enhancing the value of registry data for clinical decision-making.

Connecting Our Mob: Patient navigators As Sustainable Supports

The COMPASS (Connecting Our Mob: Patient navigators As Sustainable Supports) project concluded in June 2025. This project aimed to improve access to transplantation wait listing for Aboriginal and Torres Strait Islander people living with chronic kidney disease and kidney failure. The program employed Patient Navigators, Aboriginal and/or Torres Strait Islander people with lived experience of kidney disease to support patients from South Australia and the Northern Territory through the complex transplant system.


Royal Adelaide Hospital Patient Navigators

The project demonstrated the value of Patient Navigators from multiple perspectives: patients reported feeling more supported and better able to navigate care; clinicians noted improvements in cultural safety and communication; and health service staff observed enhanced appointment attendance and greater understanding of care pathways. It also identified key enablers and barriers to implementing these roles effectively.

Findings and ongoing evaluation informed business cases at participating sites, securing continued funding for Patient Navigator positions beyond the project's duration, including at the Royal Adelaide Hospital, South Australia's leading kidney transplantation unit. The project's outputs, recommendations, and insights for specialist health services are detailed in the Final Project Report and were recently published in *First Nations Health and Wellbeing – The Lowitja Journal.*


COMPASS project leads Kelli Own and Isabelle Hakler

In recognition of this work, project leads Kelli Owen and Isabelle Haklar received the **Advancing Equity for Aboriginal and Torres Strait Islander Peoples and Māori Award**, highlighting the project's impact in improving equity and access to kidney transplantation.

Strengthening Kidney Transplant Access for Indigenous Australians

In 2025, the National Indigenous Kidney Transplantation Taskforce (NIKTT) continued its mission to improve access to kidney transplantation for Aboriginal and Torres Strait Islander peoples.

A major milestone in 2025 was the launch of the Data Equity Dashboard, designed to support monitoring of equity across kidney care and transplantation and to track progress toward closing gaps in access and outcomes. While consultations and refinements are ongoing, the dashboard has already attracted significant interest. Early feedback suggests it will be a valuable tool to help services and stakeholders identify barriers to waitlisting and transplantation, support local quality improvement efforts, strengthen advocacy for equitable access, and inform resource mobilisation.

NIKTT also delivered the Transplantation Equity Gathering on Kaurna Yarta in early 2025, convening more than 120 participants including Aboriginal and Torres Strait Islander patients, carers and health workers, alongside non-Indigenous clinicians, advocates, researchers, and policymakers. A key outcome of the Gathering was the co-creation of the 2025 Position Statement, outlining a shared commitment and collective priorities for advancing transplantation equity. The full Gathering report is available on the NIKTT website.

Throughout the year, NIKTT sustained active engagement with ministers, the Commonwealth Department of Health, and state and territory stakeholders, advocating for ongoing funding and national implementation of its recommendations and the National Strategy for Organ Donation, Retrieval and Transplantation. Collaboration and knowledge-sharing with external partners further strengthened NIKTT's role as a national leader in improving access to kidney transplantation for Aboriginal and Torres Strait Islander peoples.

NIKTT Equity Gathering 2025

NIKTT Equity Gathering 2025 Artwork (Artist Cedric Varcoe)

Supporting Future Leaders in Nephrology Research

In 2025, ANZDATA strengthened its commitment to developing the next generation of nephrologists through the Advanced Trainee Research Project Program. Under the guidance of the Clinical Epidemiology Fellow Dr Dana Forcey, five Nephrology Advanced Trainees were selected to undertake research projects using ANZDATA datasets. This program provides critical mentorship and statistical support, particularly for trainees from centres without established research infrastructure, fostering skills in data analysis and evidence-based practice.

Research Highlights: ANZDATA Publications 2025

ANZDATA delivered a series of high-impact publications that advanced understanding of kidney disease, dialysis, and transplantation. These studies leveraged registry data and data linkage to inform clinical practice, service planning, and equity in care.

"Am I on the list?"

Medical Journal of Australia – NAIDOC Week Special Issue

Authors: McDonald S, Cundale K, Davies C, Kholmurodova F, et al.

This landmark paper examined clinician-reported reasons for non-listing of patients on the deceased-donor transplant waitlist, revealing stark disparities for Aboriginal and Torres Strait Islander peoples.

Key Findings:

- Only 2.0% of First Nations dialysis patients were waitlisted vs. 8.4% of non-Indigenous patients.
- Barriers included permanent contraindications (38%), temporary contraindications (23%), and incomplete assessments (19%).
  The authors call for culturally safe referral pathways and systemic accountability to close this gap.

Trends in Peritoneal Dialysis Demographics, Peritonitis and HD Transfer in Australia (2013–2022)

Peritoneal Dialysis International

Authors: Hopkins J, Conway A, Johnson D, Borlace M, Boudville N, Tomlins M, Chau K, Chen J, McDonald S

This registry-based study analysed PD trends over a decade.

Key Findings:

- Peritonitis rates declined from 0.40 to 0.33 infections per patient-year.
- Peritonitis-related HD transfer reduced, yet overall HD transfer increased (HR 1.03 per year).
  The disconnect between infection control improvements and HD transfer highlights systemic drivers beyond patient-level factors.

Long-Term Cardiac Surgery Outcomes in Kidney Transplant and Dialysis Patients

Journal of Nephrology

Authors: Keuskamp D, Davies C, Baker R, Reid C, Smith J, Tran L, Williams-Spence J, Wolfe R, McDonald S, Polkinghorne KR

Linked registry analysis comparing cardiac surgery outcomes in transplant vs. dialysis patients.

Key Findings:

- 5-year survival: 70% for transplant recipients vs. 49% for dialysis patients.
- Transplant recipients had 47% lower mortality risk (HR 0.53).
- Cardiac surgery increased graft loss risk, especially after severe postoperative kidney injury.

Frequency of Therapy Alerts During the First 30 Days of Automated Peritoneal Dialysis and its Relationship to Time on Treatment

Peritoneal Dialysis International

Authors: Conway A, Hopkins J, Ovenden M, Borlace M, Chen J, Sud K, Boudville N, Johnson D, McDonald S

Examined early APD therapy alerts and their impact on treatment continuity.

Key Findings:

- High alert frequency in the first 30 days predicted greater risk of HD transfer within 12 months.
- Technique survival: 78% at 1 year, 56% at 2 years, 41% at 3 years.
  Early intervention for alert burden could improve PD longevity.

The Impact of Donor and Recipient Diabetes on Patient and Graft Survival in Kidney Transplant Recipients

Kidney International Reports

Authors: Orsillo A, Kholmurodova F, Clayton P, Weightman A, Chadban S, Irish G

Assessed outcomes across donor-recipient diabetes combinations in 11,343 transplants.

Key Findings:

- Both donor and recipient diabetes (D+/R+) significantly worsened graft survival (HR 1.70) and patient survival (HR 1.77).
- Kidneys from diabetic donors remain viable for non-diabetic recipients, but D+/R+ pairs require caution.

Australia & New Zealand Living Kidney Registry (ANZLKD)

The Australia and New Zealand Living Kidney Donor Registry (ANZLKD) continues to monitor the safety and long-term health of living kidney donors across Australia and New Zealand, providing critical evidence to support donor safety guidelines and follow-up care. Living kidney donation is a community-driven act, and the Registry maintains a strong focus on engagement with donors, their families, and the broader public to ensure the ongoing support of this vital program.

In 2025, ANZLKD strengthened consumer involvement in its governance through the addition of a consumer representative to the Living Kidney Working Group. This complements ongoing efforts to incorporate donor and community perspectives into the development, interpretation, and communication of registry outputs.

A key initiative for the Registry remains strengthening long-term data collection, ensuring consistent monitoring of donor health over time. Monthly data continue to be collected and reported to stakeholders and the community, with final, validated data presented annually in the ANZDATA Registry Annual Report. These efforts support transparency, inform best practice in donor care, and underpin evidence-based decision-making across the kidney transplant sector.

Australia & New Zealand Organ Donor Registry (ANZOD)

The Australia and New Zealand Organ Donation Registry (ANZOD) continued to collect and report national organ, eye and tissue donation data, supporting clinicians, health services, researchers and policy makers across Australia and New Zealand. Established in 1989, ANZOD remains the central source of donation data and sector reporting.

A major focus during 2025 was the first comprehensive review of the ANZOD Annual Report since the Registry's inception. Under the leadership of ANZOD Working Group co-chairs Dr Georgina Irish and Dr Helen Opdam, the Working Group undertook an extensive program of review and redevelopment. This included a two-day, in-person workshop at which the entire Annual Report was systematically reviewed, followed by meetings throughout the year to progress and refine this work.

The review examined report structure, chapter content, data presentation, terminology and alignment with contemporary sector needs. This substantial body of work will culminate in the release of a completely redeveloped ANZOD Annual Report in 2026, representing a comprehensive overhaul of existing chapters and reporting approaches.

In parallel, the registry team undertook a significant redevelopment of waitlisting data reporting, marking the first implementation of dashboard-based reporting within the Registry. This transition from traditional report-based outputs has improved the accessibility, usability and transparency of waitlisting information, enabling more effective analysis of trends and activity. View the dashboard here.

Australia & New Zealand Heart Transplant Registry (ANZHTR)

Australia & New Zealand Lung Transplant Registry (ANZLUNG)

In 2025, the Australia and New Zealand Heart Transplant Registry (ANZHTR) and the Australia and New Zealand Lung Transplant Registry (ANZLUNG) continued work to establish national reporting of heart and lung transplantation activity and outcomes. During the year, registry leadership transitioned to Dr Phil Clayton, bringing strong statistical expertise across both registries.

Throughout 2025, work continued to finalise data collection processes, with a focus on completing historical and contemporary datasets, resolving data quality issues, and preparing both registries for data lock. Progress was incremental but steady, reflecting the complexity of retrospective data integration and the need for consistent data validation across transplanting sites. By the end of the reporting period, both registries are well positioned for data lock in 2026 and the subsequent release of their first individual reports.

The work undertaken in 2025 represents an important consolidation phase, laying the groundwork for providing a strong foundation for renewed national reporting, enabling improved understanding of transplant activity and outcomes in the field of Heart and Lung Transplantation.

Australia & New Zealand Eye & Tissue Donation Registry (ANZETD)

In 2025, the Australia and New Zealand Eye and Tissue Donation Registry (ANZETD) continued to provide national reporting on eye and tissue donation and transplantation activity, supporting sector oversight and performance monitoring. Data collection and reporting remained essential to understanding activity levels, identifying trends, and assessing progress towards self-sufficiency in eye and tissue donation, in line with the objectives of the National Eye and Tissue Sector Framework.

Throughout the year, ANZETD worked closely with the Australian Organ and Tissue Authority (OTA), public and private eye and tissue banks, and professional bodies including the Eye Bank Association of Australia and New Zealand (EBAANZ) and the Biotherapeutics Association of Australasia (BAA). Reporting processes were further refined to improve data quality and consistency, particularly within the eye donation and transplantation sector.

In alignment with Priority Area 4 of the National Eye and Tissue Sector Framework, ANZETD supported the ETAC Data Working Group, contributing to Phase 1 of the ETAC Data Reporting Project by reviewing and progressing an expanded minimum eye and tissue data set, including the development and presentation of a minimum mandatory data set and agreement on an iterative approach to future data development and national reporting. This work will continue into 2026 as the project progresses through subsequent phases.

Australian Particle Therapy Clinical Quality Registry – TROG 21.12 (ASPIRE)

ASPIRE Australian Particle Therapy Clinical Quality Registry

The Australian Particle Therapy Clinical Quality Registry -TROG 21.12 (ASPIRE) has been established as Australia's first national radiation therapy clinical quality registry, designed to compare treatment practices and outcomes of patients treated with currently available Photon (x-ray) Radiation Therapy (XRT) compared with Proton Beam Therapy (PBT) data once PBT becomes available in Australia.

PBT is an advanced form of radiation therapy requiring significant capital expenditure, and as such will be a controlled healthcare resource available only to those patients who meet strict evidenced based criteria. Despite the known ability of PBT to reduce radiation doses to healthy tissues relative to conventional radiation therapy with X-rays (XRT), due to a number of factors including the high cost of PBT and relative lack of availability, there is a paucity of high-level clinical data demonstrating superior safety of PBT over XRT. To address this, during the application to have new PBT item numbers added to the Medicare Benefits Schedule (MBS) under Medical Services Advisory Committee (MSAC) application 1638 in 2020, the Commonwealth Department of Health recommended a national registry be implemented to compare the clinical outcomes of XRT with PBT.

There are currently nine sites approved and awaiting site activation in early 2026 or actively enrolling patients diagnosed with a cancer that will be eligible for PBT under MSAC 1638, but currently being treated with XRT before PBT is available:

- Royal Adelaide Hospital with Women's and Children's Hospital, South Australia - recruiting
- Alan Walker Cancer Care Centre, Northern Territory - recruiting
- Sir Charles Gairdner Hospital, Western Australia - recruiting
- Melbourne Children's Hospital, Victoria – recruiting
- Canberra Hospital, Australian Capital Territory - recruiting
- ICON Cancer Centre, National network – recruiting at Windsor Gardens, Noarlunga, North Adelaide
- Royal Brisbane and Women's Hospital, Queensland – Approved and site activation planned for early 2026

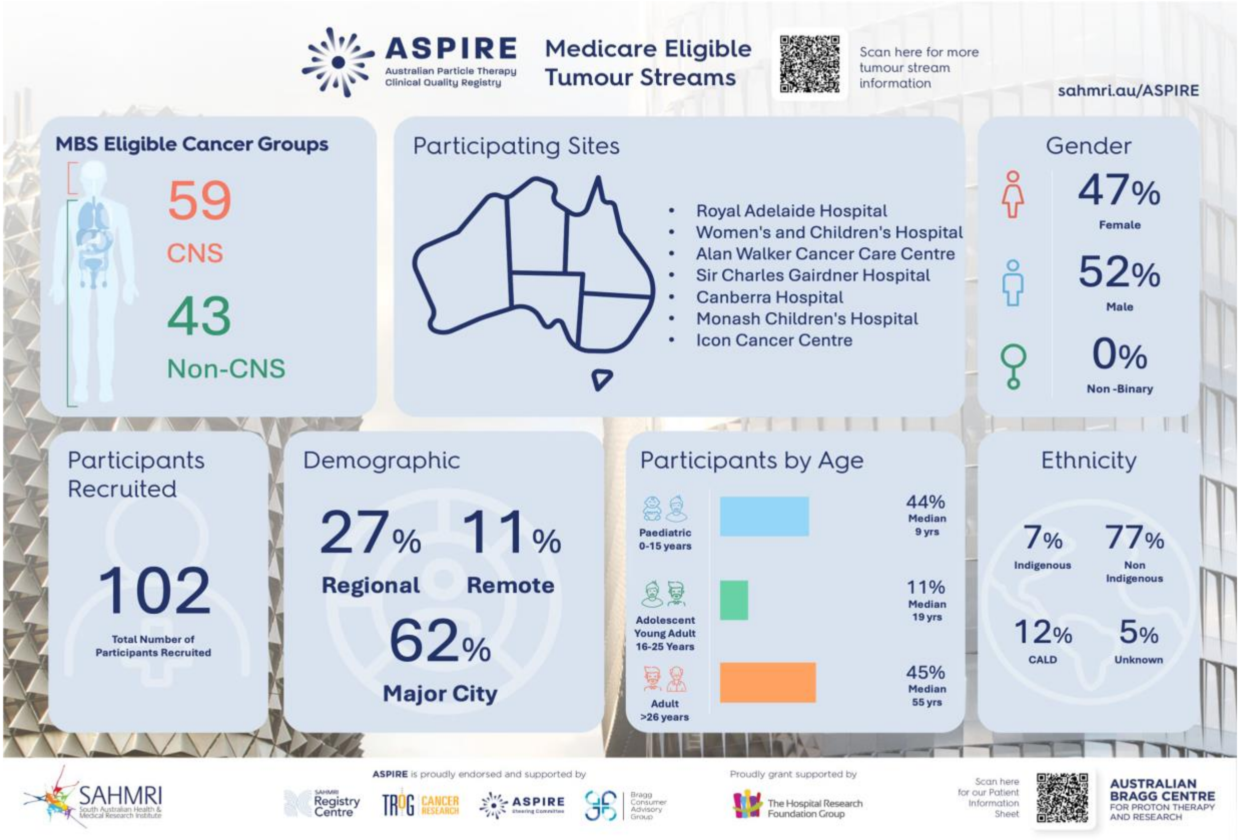
ASPIRE continued its expanded data collection at the Royal Adelaide Hospital for tumour streams not currently funded under MSAC, but which are treated with PBT internationally. Ongoing recruitment of these indications has enabled the collection of critical real-world evidence to support the future expansion of PBT eligible indications, consistent with priorities outlined in Cancer Australia's – '*Strategy for Proton Beam Therapy for Cancer Patients in Australia*' August 2023.

This year, data collected on ASPIRE was used to deliver a translational feasibility study evaluating how international PBT selection frameworks could be applied to an Australian breast cancer population. De-identified registry data from 92 participants with left-sided breast cancer treated with XRT at a participating ASPIRE site between January and November 2024 were extracted, quality-assured, and analysed, including verification of clinically delivered treatment plans and cardiac dosimetry. The Netherlands' nationally adopted model-based selection criteria for breast cancer was applied, incorporating mean heart dose, treatment volumes, cardiac risk factors, and exposure to cardiotoxic systemic therapies. This analysis identified a subset of patients who met the international criteria for comparative proton planning, with selection rates comparable to those reported in the Dutch clinical experience. This work demonstrates ASPIRE's role in generating high-quality real-world evidence, supporting international benchmarking, and informing future service planning and policy development ahead of the national introduction of particle therapy.

The Australian Particle Therapy Clinical Quality Registry is proudly:

- Sponsored by The Hospital Research Foundation Group
- Endorsed by the Trans-Tasman Radiation Oncology Group – TROG Cancer Research, Trial no. 21.12
- Registered with the Australian and New Zealand Clinical Trials Registry (ANZCTR)
- Recognised and endorsed by the Australian Commission on Safety and Quality in Health Care
- Supported by the ASPIRE National Steering Committee.

The study has been approved by the Central Adelaide Health Network Human Research Ethics Committee under the National Mutual Agreement scheme on February 2nd, 2022 (2021/HRE00394).
Participant recruitment on the registry commenced in March 2022.



ASPIRE Australian Particle Therapy Clinical Quality Registry

Medicare Eligible Tumour Streams

Scan here for more tumour stream information

sahmri.au/ASPIRE

MBS Eligible Cancer Groups

59 CNS

43 Non-CNS

Participating Sites

- Royal Adelaide Hospital
- Women's and Children's Hospital
- Alan Walker Cancer Care Centre
- Sir Charles Gairdner Hospital
- Canberra Hospital
- Monash Children's Hospital
- Icon Cancer Centre

Gender

47% Female

52% Male

0% Non-Binary

Participants Recruited

102

Total Number of Participants Recruited

Demographic

27% Regional

11% Remote

62% Major City

Participants by Age

Group	Share
Paediatric 0-15 years	44% Median 9 yrs
Adolescent Young Adult 16-25 Years	11% Median 19 yrs
Adult >26 years	45% Median 55 yrs

Ethnicity

7% Indigenous

77% Non Indigenous

12% CALD

5% Unknown

ASPIRE is proudly endorsed and supported by

Proudly grant supported by The Hospital Research Foundation Group

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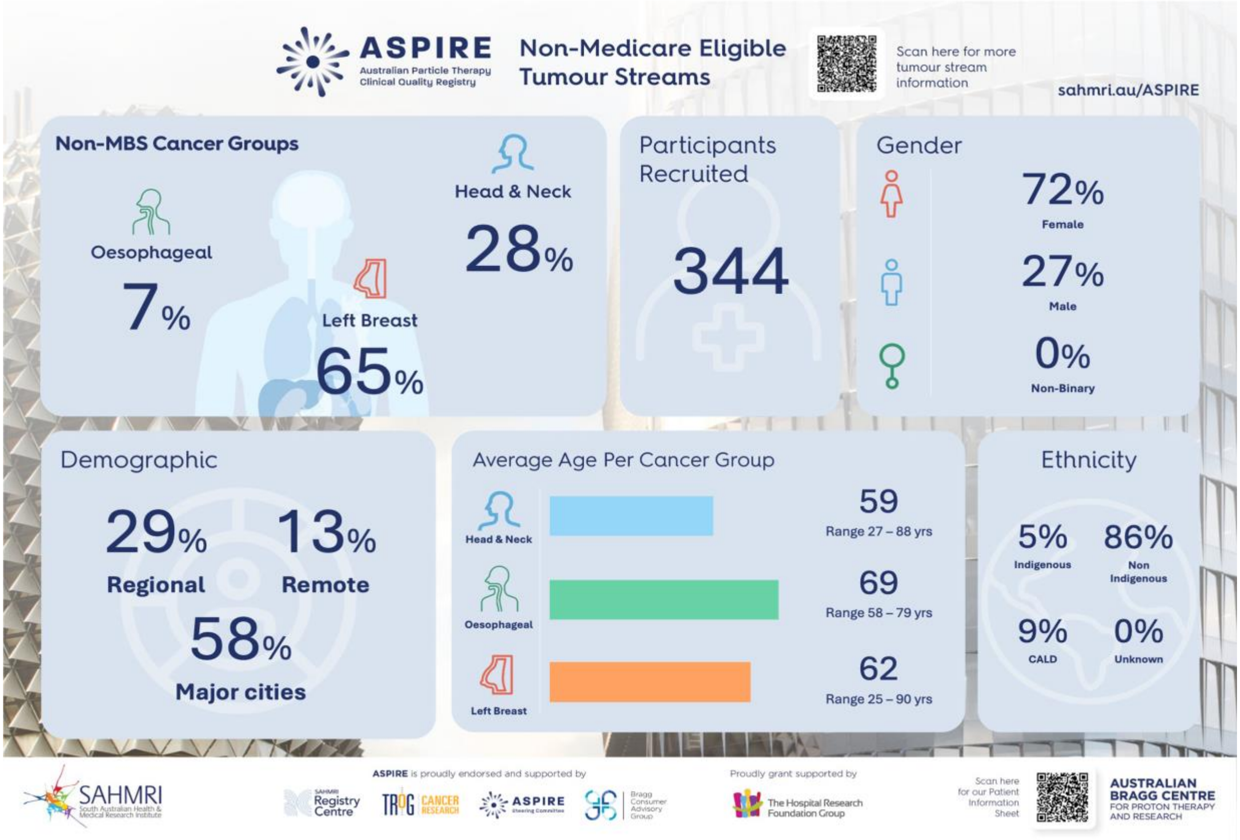
AUSTRALIAN BRAGG CENTRE FOR PROTON THERAPY AND RESEARCH



ASPIRE Australian Particle Therapy Clinical Quality Registry

Non-Medicare Eligible Tumour Streams

Scan here for more tumour stream information

sahmri.au/ASPIRE

Non-MBS Cancer Groups

Oesophageal 7%

Head & Neck 28%

Left Breast 65%

Participants Recruited

344

Gender

72% Female

27% Male

0% Non-Binary

Demographic

29% Regional

13% Remote

58% Major cities

Average Age Per Cancer Group

Group	Average age
Head & Neck	59 Range 27 – 88 yrs
Oesophageal	69 Range 58 – 79 yrs
Left Breast	62 Range 25 – 90 yrs

Ethnicity

5% Indigenous

86% Non Indigenous

9% CALD

0% Unknown

ASPIRE is proudly endorsed and supported by

Proudly grant supported by The Hospital Research Foundation Group

Scan here for our Patient Information Sheet

AUSTRALIAN BRAGG CENTRE FOR PROTON THERAPY AND RESEARCH

ANZ Emergency Laparotomy Audit – Quality Improvement (ANZELA-QI)

Royal Australasian College of Surgeons

National Expansion & Enhanced Capacity

During 2025, ANZELA-QI received funding through the Department of Health, Disability and Ageing's National Clinical Quality Registry Program. The funding will enhance our capacity to expand participating sites nationally, strengthen data infrastructure and analytics, and increase capacity to support quality improvement activities. To drive this transformation, ANZELA-QI appointed a Clinical Data Analyst (January 2026) and a Project Lead, Operations (February 2026), strengthening data quality processes, reporting capabilities and operational oversight. A priority will be to build a near real-time dashboard.

Governance Strengthening & Strategic Oversight

ANZELA-QI successfully transitioned from a Working Group to a formal Steering and Management Committee, establishing robust governance arrangements and enhancing strategic oversight of the registry. Membership was appointed through an open expression of interest process and includes representation from multidisciplinary team of clinicians, Departments of Health, consumer and Indigenous community representatives, as well as professional colleges and societies committed to surgical care and data quality.

Insightful Reporting

The Third ANZELA-QI National Report (2022–2024) was published in November 2025, highlighting significant variation in emergency laparotomy care across participating hospitals. National risk-adjusted in-hospital mortality was 6.9%, aligning with international benchmarks, yet varied ten-fold across hospitals. Only 60% of urgent cases reached theatre within 18 hours, and frailty assessment was completed in just one-quarter of patients aged ≥65 years. The findings highlight ongoing opportunities to reduce unwarranted variation through standardised pathways and national audit participation.

National Engagement & Influence

ANZELA-QI strengthened its national profile through key contributions in 2024-2025. The ANZELA Chair presented at the ACTA Clinical Trials and Registries Symposium (December 2024), sharing methodology on data quality assessment and lessons learned. ANZELA-QI also provided audit-based evidence and feedback to the ACSQHC Emergency Laparotomy Clinical Care Standard, which underwent public consultation in 2025, with the final standards expected mid-2026. These activities position ANZELA-QI to continue supporting improvements in emergency laparotomy care across Australia and New Zealand.

Patient & Family Involvement

ANZELA-QI commenced planning for a Patient and Family Involvement Group (PAFIG), modelled on the National Emergency Laparotomy Audit (NELA). A call for expressions of interest will be issued to recruit patients, carers and consumer representatives. The PAFIG will provide advice on registry priorities and patient-facing outputs, supporting transparency, strong governance, and the relevance of audit findings to patients and families.

Australasian Registry of ECGs of National Athletes (ARENA)

The ARENA (Australasian Registry of Screening ECGs in National Athletes) project aims to improve our understanding of the clinical outcomes of screening and the boundaries between normal and abnormal ECG features in athletes across different sexes, ethnicities, ages, and sports. ARENA was launched just over 2 years ago, in November 2023. In its first 2 years of operation, ARENA has recruited 5 national sporting organisations and has collected data from over 5,000 athlete cardiac screenings.

Key publication, prize & changes to guidelines:

ARENA published its first results paper the *Journal of the American Heart Association*, which was presented at the American College of Cardiology Care of the Athletic Heart conference, the European Society of Preventive Cardiology conference, the International Athlete ECG Summit and the Cardiac Society of Australia and New Zealand annual scientific meeting, where it won the CSANZ Allied Health, Science & Technology Prize. This paper showed that the most common abnormality in female athletes' ECGs (T wave inversion confined to leads V2 and V3) was not associated with diagnoses of cardiac pathology. This paper is consistent with previous research and will be cited as the basis for updates to athlete ECG interpretation criteria, to be released in 2026.

Publications

Orchard JJ, Drezner JA, Raju H, Puranik R, Gray B, Brosnan M, Doughty RN, Hamilton B, Driscoll T, Davis AJ, Buckthorpe E, Eggleton S, Baggish A, La Gerche A, Orchard JW. Isolated Anterior T-Wave Inversion in Elite Athletes: Prevalence and Clinical Relevance by Sex and Sporting Discipline. *J Am Heart Assoc*. 2025 Oct 7;14(19):e042435. doi: 10.1161/JAHA.125.042435. Epub 2025 Sep 30. PMID: 41025448; PMCID: PMC12684483.

Qualified privilege:

ARENA was declared a federal quality assurance activity in 2025 under the *Health Insurance Act 1973* (Cth).

Researchers at ARENA are now focussing on the impact of changes to athlete ECG criteria and how this will change the proportion of athletes requiring further evaluation. Work continues to support quality improvement initiatives in participating sporting organisations.

2025 ARENA Snapshot

Total cardiac screenings: ~5,000
Athletes: 46% female / 54% male
Participating organisations: 5
Sports: 37
Publications: 2
Abstracts: 4
Presentations: 18

Coronary Angiogram Database of SA (CADOSA)

CADOSA
Coronary Angiogram Database of South Australia

The Coronary Angiogram Database of South Australia (CADOSA) is a statewide clinical quality registry capturing consecutive public hospital patients undergoing coronary angiography and/or percutaneous coronary intervention (PCI) across South Australia. CADOSA provides a comprehensive platform for quality improvement, service evaluation, and research spanning the full spectrum of invasive coronary care.

The Registry Program comprises three integrated components:

- Clinical Outcomes: Detailed clinical information is collected for each patient through structured interviews and systematic case-note abstraction during hospital admission. Subsequent clinical events are ascertained through jurisdictional data linkage over a 12-month follow-up period.
- Patient Health Outcomes: In selected cohorts, patient-reported outcome measures (PROMs) assessing cardiac symptoms, health-related quality of life, and depressive symptoms are collected during admission and reassessed at 1 and 12 months via telephone follow-up.
- Biobank: In selected patients, biological samples are collected and stored to support genetic, molecular, and bioassay research, enabling discovery science and future precision medicine initiatives.

Collectively, this infrastructure underpins ongoing monitoring of cardiac catheterisation services, supporting evaluation of procedural safety, clinical performance, and appropriateness of care. Research, innovation, and translation into practice remain core pillars of the CADOSA Registry Program.

CADOSA maintains strong national collaborations, including its partnership with the National Cardiac Registry (NCR), an Australian Government Department of Health initiative that consolidates PCI activity nationwide. In 2025, CADOSA contributed South Australian public hospital PCI data to the NCR Annual Status Report for 2024, supporting national benchmarking and transparency in cardiac care delivery. https://nationalcardiacregistry.org.au/2025-annual-status-report/

PAMICO Project – SA Health Awards 2025: Winner of the Minister's Award for Innovation.

A major highlight in 2025 was the national recognition of the PAMICO Project (Personalising Acute Myocardial Infarction Care to Improve Outcomes), which received the Minister’s Award for Innovation at the SA Health Awards https://www.calhn.sa.gov.au/news/sa-health-awards-winners. This world-first initiative transformed heart attack care by embedding personalised, data-driven risk assessment into routine clinical workflows, enabling more tailored treatment and improved patient outcomes.

PAMICO was delivered through an NHMRC Partnership Grant led by CADOSA investigators Professor John Beltrame, Associate Professor Rosanna Tavella, Professor Chris Zeitz, and international collaborator Professor John Spertus, with critical support from CALHN nursing staff Philip Cerna, Katherine Hines, and Samuel Kitto. The project integrated predictive risk models directly into the care of patients undergoing coronary angiography for acute myocardial infarction (MI), providing real-time estimates of key outcomes such as length of hospital stay, bleeding risk, and acute kidney injury.

These tools informed immediate clinical decision-making and prevention strategies. For example, contrast volume during angiography was individualised to balance diagnostic quality with minimisation of renal risk. Alongside real-time risk stratification, CADOSA registry data continued to support regular clinician feedback and benchmarking, demonstrating strong adherence to evidence-based care across CALHN cardiology services for acute MI patients.

The PAMICO intervention was associated with substantial improvements in patient outcomes, including a 46% reduction in bleeding complications, a 15% decrease in acute kidney injury, and a 45% reduction in 30-day major adverse cardiovascular events. Clinicians reported improved discharge planning, enhanced identification of high-risk patients, and greater confidence in tailoring treatment strategies. In an Australian first, patients also received personalised consent documentation outlining anticipated risks and expected discharge timelines, strengthening shared decision-making and patient engagement.

The PAMICO Project Team accepting the Ministers Award for Innovation at the 2025 SA Health Awards.
From left – Prof Chris Zeitz, Philip Cerna, A/Prof Rosanna Tavella, Samuel Kitto and Prof John Beltrame.

Postgraduate Research Training and Capacity Building

CADOSA continues to play a significant role in postgraduate research training, having supported more than 12 PhD candidates to date. In 2025, four PhD candidates were actively utilising CADOSA data and infrastructure for their doctoral research.

In 2025, PhD candidate Dr Sarena La received a Dean's Commendation for Doctoral Thesis Excellence for her thesis, *Clinical Insights into the NOCA Syndromes.* CADOSA is among a small number of registries internationally that capture diagnostic coronary angiography in addition to interventional procedures, creating unique opportunities to study patients with non-obstructive coronary arteries (NOCA), including myocardial infarction with non-obstructive coronary arteries (MINOCA), and angina with non-obstructive coronary arteries (ANOCA) presentations.

Dr La's work examined the clinical journey of NOCA patients, from symptom onset and invasive assessment through to longer-term clinical outcomes and patient-reported health status. Her research identified important gaps in diagnostic pathways, under-utilisation of appropriate investigations, and a high burden of persistent angina symptoms in this population. Building on this work, Dr La was awarded a Heart Foundation Kick Start Fellowship (2025–2027) to continue research aimed at improving outcomes and advocacy for patients living with NOCA syndromes.

BreastSurgANZ Quality Audit (BQA)

BreastSurgANZ QUALITY AUDIT

The BreastSurgANZ Quality Audit (BQA) aims to improve the quality of surgical care for patients with early and locally advanced breast cancer in Australia and Aotearoa New Zealand. The BQA has been in operation since 1998, there are currently 338 members submitting over 15,000 cases annually to the registry. Surgeons can self-assess their clinical performance against set key performance indicators (KPIs). Research into breast cancer treatment and outcomes using de-identified data forms an important part of the registry's value. Breast Surgeons of Australia and New Zealand require members to submit data on all cases of early and locally advanced breast cancer.

Key milestones

- Qualified privilege in Aotearoa New Zealand was reinstated in January 2025 after approval in 2024.
- A new application for qualified privilege in Australia was submitted, approved and reinstated in November 2025.
- A record 24 requests for data, 17 for research, 3 for quality assurance and 4 for data checking and administration. A total of 22 requests were approved for release.
- Introduced annual Individual Member Reports to all members – encouraging members to review their KPI performances.
- Received funding from the Syndey Breast Cancer Foundation for a Research Project Officer.

Postural Orthostatic Tachycardia Syndrome (POTS) Registry

The Australian **Postural Orthostatic Tachycardia Syndrome (POTS) Registry** continues to support high quality research output to improve care for those living with POTS in Australia. Led by the Australian POTS Foundation in partnership with academic and clinical collaborators, the Registry is the first national adult POTS registry internationally to capture comprehensive baseline and longitudinal data. It captures high-quality, patient-reported and clinical data to characterise diagnostic pathways, symptom burden, comorbidities, quality of life, and health-system impacts of POTS in Australia. Registry data are actively translated into peer-reviewed publications, workforce education, policy engagement, and clinical practice improvement.

Publications

In 2025, data from the Australian POTS registry directly informed peer-reviewed publications that advanced understanding of POTS in the Australian context and contributed to a growing international body of literature.

Lau DH, Fedorowski A, Raj SR, Schild C, Pace LA, Blitshteyn S, Raj V, Boris JR, Kavi L, Seeley MC, Gallagher C. Postural Orthostatic Tachycardia Syndrome: A State-of-the-Art Review. *Heart Lung Circ*. 2026 Jan 9:S1443-9506(25)01654-3. doi: 10.1016/j.hlc.2025.09.004. Epub ahead of print. PMID: 41519610.

Wilson G, Seeley MC, Slater P, Lau DH, Gallagher C. Characterising Postural Orthostatic Tachycardia Syndrome (POTS) triggered by a viral illness compared to concussion or trauma. *Clin Auton Res.* 2025 Aug;35(4):637-641. doi: 10.1007/s10286-025-01136-6. Epub 2025 Jun 21. PMID: 40543010.

Seeley MC, Wilson G, Ong E, Langdon A, Chieng J, Bailey D, Comacchio K, Page A, Lau DH, Gallagher C. Symptom burden, quality of life, and diagnostic journey of people with postural orthostatic tachycardia syndrome, Australia, 2021-24: a descriptive patient registry data study. *Med J Aust*. 2025 Jun 18;223(3):159–60. doi: 10.5694/mja2.52710. Epub ahead of print. PMID: 40533427; PMCID: PMC12318489.

Seeley MC, Wilson G, Ong E, Langdon A, Chieng J, Bailey D, Comacchio K, Page AJ, Lau DH, Gallagher C. Biological sex-dependent differences in postural orthostatic tachycardia syndrome. *Eur J Cardiovasc Nurs*. 2025 Jul 21;24(5):762-771. doi: 10.1093/eurjcn/zvaf048. PMID: 40138180.

Seeley MC, O'Brien H, Wilson G, Coat C, Smith T, Hickson K, Casse R, Page AJ, Gallagher C, Lau DH. Novel brain SPECT imaging unravels abnormal cerebral perfusion in patients with postural orthostatic tachycardia syndrome and cognitive dysfunction. *Sci Rep*. 2025 Jan 28;15(1):3487. doi: 10.1038/s41598-025-87748-4. PMID: 39875497; PMCID: PMC11775248.

Awards and Recognition

Registry-related research and leadership received significant national and international recognition in 2025, including:

- **Dr Marie-Claire Seeley awarded the PhD Research Excellence Award** at the **South Australian Science Excellence and Innovation Awards**, recognising outstanding doctoral research informed by Registry-related work.
- **Cardiovascular Nursing Prize** awarded to **Dr Marie-Claire Seeley** by the **Cardiac Society of Australia and New Zealand**, acknowledging leadership and impact in autonomic and cardiovascular nursing research.
- **Best Clinical Poster** awarded to **Gemma Wilson** at the **Australasian Society of Autonomic Neuroscience**, recognising excellence in Registry-informed clinical research dissemination
- **Best Poster** awarded to **Gemma Wilson** at the **South Australian Cardiovascular Research Network Showcase.**
- A **Churchill Fellowship** awarded to **Dr Marie-Claire Seeley** to examine international best practice in autonomic testing and care models, supporting translation of global expertise into the Australian healthcare system.

Successes and Impact

In 2025, the Australian POTS Registry demonstrated measurable impact across research, clinical practice, and advocacy by:

- Establishing a robust national evidence base for POTS in Australia
- Supporting improved clinical recognition and consistency of diagnosis
- Informing development of GP education resources and clinical pathways
- Building national research capacity in autonomic disorders
- Strengthening Australia’s international profile in registry-based POTS research.

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

SA Birth Defects Register (SABDR)

Government of South Australia
Women's and Children's Health Network

Women's & Children's Hospital

The South Australian Birth Defects Register is a population-based collection of information on congenital anomalies, including cerebral palsy. The Register collects information on all children born in South Australia on or after 1st January 1986 who have a significant congenital anomaly detected in the first five years of life.

It is noteworthy that the percentage of total births with congenital anomalies has not changed significantly since the Register began to collect data in 1986, with the overall rate of congenital anomalies in South Australia remaining steady at around 6%.

The SABDR's contributions of non-identified data to the National Congenital Anomalies Data Collection, hosted by the Australian Institute of Health and Welfare, continue to be provided. Based on data from 7 jurisdictions around Australia, the latest web-based report of Congenital Anomalies in Australia presents data for birth years 2016-2019 with data from more recent years currently being prepared and processed by the AIHW.

The SABDR continues to contribute to multiple research projects, including large-scale linkages for studies investigating assisted reproductive technologies, and other health outcomes for families.

SA Cerebral Palsy Register (SACPR)

Government of South Australia
Women's and Children's Health Network

Women's & Children's Hospital

The South Australian Cerebral Palsy Register is a population-based collection of information on children with cerebral palsy born in South Australia. In 2025, the latest annual SACPR report was published, presenting information for children with cerebral palsy born in the years 1993-2019. This report showed that the prevalence of cerebral palsy in South Australia has decreased from a rate of 2.34 per 1,000 live births (1993-1995) to 1.98 per 1,000 live births (2017-2019). This is in line with data presented by the Australian Cerebral Palsy Register, which reported a sustained overall rate for Australia of 1.5 per 1,000 live births, the lowest in the world.

The SACPR remains an active and contributing member of the Australian Cerebral Palsy Register. Established in 2008, the ACPR has grown to be the largest database of its kind in the world. The latest Australian Cerebral Palsy Register prevalence data was published in early 2025 and demonstrates the current prevalence trends for cerebral palsy across Australia.

During 2025, a focus for the team has been the implementation of alternative ways for clinicians and families to complete a medical assessment for children with a diagnosis of cerebral palsy. This assessment has traditionally been filled in on paper forms by paediatric rehabilitation specialists during scheduled appointments. Register staff are now able to offer clinicians more streamlined and digital access to these forms, which is hoped will improve the experience for both clinicians and families.

The SACPR continues to contribute to research projects, including providing assistance with recruitment to studies such as the CP Achieve study, and also continues to provide non-identified data as part of linkage projects.

The Australia and New Zealand Vasculitis Quality and Disease Registry (ANZVASC-QDR)

ANZVASC
Australia and New Zealand Vasculitis Society

The Australia and New Zealand Vasculitis Quality and Disease Registry (ANZVASCQDR) was founded by members of the ANZ Vasculitis Society (ANZVASC). It aims to improve the quality of care of people with vasculitis. Monash University is the host and data custodian.

The ANZVASC-QDR remains at this stage focussed those with ANCA-associated vasculitis (AAV), with some participants with large vessel vasculitides being enrolled recently.

Following an EOI for new sites, the Registry now has eight active sites (including 3 in New Zealand) and a further eight sites at various stages of the governance process. Approximately 250 participants have been enrolled with a median follow-up (AAV) of two years (maximum 9 years).

Members of the registry, together with other clinicians and consumers have completed a priority setting exercise to determine the key reporting outcomes for the ANZVASC-QDR. Outcomes include patient reported outcomes and clinically defined outcomes. Round 1 attracted over 200 participants from Australia, New Zealand, the UK and Ireland, with over 80% of participants completing all three rounds to prioritise 8 outcomes for reporting.

Presentations

ANZSN Congress in 2025

22nd International Vasculitis Workshop (in late February 2026).

Staff

As of early 2026, the ANZVASC-QDR is still looking employ a part time registry database manager who will be able, not only to manage the registry as it grows, but also help train new sites.

International Vitreoretinal B-cell Lymphoma Registry (IVRLR)

Flinders
UNIVERSITY

Vitreoretinal lymphoma is a non-Hodgkin B-cell lymphoma that affects the posterior portion of the eye. Vision loss is common, and the median survival is approximately 2 years. Because vitreoretinal lymphoma is rare, robust randomised controlled clinical trials are not feasible. By collecting and analysing high quality real-world data on current diagnostics, treatments and outcomes of vitreoretinal lymphoma, the aim of the *International Vitreoretinal B-Cell Lymphoma Registry* is to identify the most effective management approaches.

The *International Vitreoretinal B-Cell Lymphoma Registry* continues to build momentum from its modest beginnings. In 2025, we continued to direct considerable effort towards expanding our co-investigator network. At the end of 2024, there were 66 ophthalmologists and other expert clinicians (from 18 countries) actively contributing to the project, in addition to the local research team. We worked at several of what will be our first series of substantial articles focused on clinical approaches, outcomes, and clinical predictors of outcomes, with one paper already under peer review. A clinician-scientist HDR student member of the team is leading a major PROSPERO-logged systematic review and network meta-analysis that will provide bibliographic support to the effort, and we are also undertaking a practice pattern survey supported by our international clinical ambassadors and patient advocate.

Australian and New Zealand Audit of Surgical Mortality (ANZASM)

The Australian and New Zealand Audit of Surgical Mortality (ANZASM) provides independent evaluation of the surgical care offered to patients that die in hospital. With support from state and territory departments of health and through the engagement of surgeons, ANZASM collects data on patient in-hospital mortality and the quality of surgical care that they received. Through this process ANZASM produces feedback that informs surgeons and departments of health for improved surgical care. ANZASM is managed by the Royal Australasian College of Surgeons (RACS) in all Australian states and territories except for NSW.

As of 31 December 2025, ANZASM had facilitated the review of 65,154 instances of patient in-hospital mortality where surgical care was involved (since its inception), with a further 9,347 cases excluded from the full review process due to being terminal care admissions. The median age of these patients was 77 years (interquartile range 66–86), they were 56.4% male and constituted emergency presentations with an acute life-threatening condition in 85.3% of cases. In terms of risk profile, 85.4% of patients presented with an ASA score (American Society of Anesthesiologists physical classification system) of 3 or higher, with 87.6% of patients having at least one comorbidity. Following independent review, it was considered that in 19.7% of cases clinical management could have been improved. The two main areas for improvement were operative management issues and operative decision.

This process has helped inform the recommendations made in reports and the educational events ANZASM has held over the past year, including bi-monthly webinars addressing the complexities of patient transfer, preventing and managing hospital acquired infections and the impact of non-technical competencies on patient outcomes. ANZASM released monthly Case Note Reviews along with three National Case Note Review Booklets, themes included transferred cases and non-technical errors.

South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC)

SA-PCCOC
South Australian
Prostate Cancer
Clinical Outcomes Collaborative

The South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC) registry continued to make advance throughout 2025. The team has maintained excellent recruitment rates with the registry now holding data on over 24,000 men diagnosed with prostate cancer and a new set of data processing tools have been introduced through the SA Health Data Analytics Platform (DAP).

SA-PCCOC co-hosted the 2025 SA Prostate Cancer Research Symposium which attracted researchers and clinicians from across the state and was made possible by generous industry sponsorship. Our guest speaker was Associate Professor David Smith from the Cancer Council NSW, who provided an update on Australia’s PSA testing policy.

SA-PCCOC continues to grow its research output with 12 papers in 2025 and provides mentorship for seven postgraduate students. This research activity works towards achieving better health outcomes for patients in Australia and also helps grow the medical workforce treating these patients. Highlights include the first randomised controlled trial testing an intervention and recruiting from the registry and expanded data linkage activities. The registry acknowledges generous support from the Movember Foundation, The Hospital Research Foundation, and the Urological Society of Australia and New Zealand (SA-NT section).

Australian and New Zealand Registry of Advanced Glaucoma (ANZRAG)

AUSTRALIAN & NEW ZEALAND
REGISTRY OF ADVANCED GLAUCOMA

The Australian and New Zealand Registry (ANZRAG) aims to identify novel genetic risk factors for glaucoma blindness and has recruited 9918 individuals over the past 18 years. The recruitment is ongoing with an additional 350 participants recruited over the past 12 months in all categories of the registry: Advanced Glaucoma, Pseudoexfoliation Syndrome, Primary Congenital Glaucoma, Steroid Response Glaucoma, Angle Closure, Anterior Segment Dysgenesis, Pigment Dispersion Glaucoma, Non-Advanced Open-Angle Glaucoma (including suspects), Disc Drusen, Nanophthalmos, and family members of recruits.

The most prevalent participants were Advanced Glaucoma (34%), followed by Non-Advanced Open-Angle Glaucoma (25%), and then early Glaucoma suspects (20%). Specialists (n=249) from across Australia and New Zealand have referred participants to ANZRAG. Participants from every state and territory and internationally, including New Zealand, Canada and the UK have been recruited and provided DNA samples.

We continue to conduct genetic testing through NATA-accredited laboratories of SA Pathology at Flinders Medical Centre and have characterised the phenotype with glaucoma-associated genes. The cohort has been included in a number of and international presentations and publications. Our focus for 2025 was centred around further understanding and increasing the utility of glaucoma associated polygenic risk scores (PRS). Of note, the Chief Investigator, Professor Jamie Craig, was awarded the status of South Australian Scientist of the Year for 2024-2025 for his work in this field.

Professor Jamie Craig pictured on right

Publications

Kolovos A, Qassim A, Marshall HN, et al. A Multitrait Polygenic Risk Score for Open-Angle Glaucoma Stratifies Risk of Pigmentary Glaucoma in Pigment Dispersion Syndrome. *Ophthalmol Glaucoma.* 2025 Oct 21:S2589-4196(25)00216-9. doi: 10.1016/j.ogla.2025.10.005. Epub ahead of print.

Luben RN, Biradar MI, Stuart KV, et al. A Multitrait Open-Angle Glaucoma Polygenic Risk Score Stratifies Risk of Glaucoma Diagnosis and Severity in Eyes with Pseudoexfoliation. *Ophthalmology*. 2025 Aug;132(8):878-887. doi: 10.1016/j.ophtha.2025.02.013. Epub 2025 Feb 24. PMID: 40010646.

Kolovos A, Qassim A, Hassall MM, et al. A Multitrait Open-Angle Glaucoma Polygenic Risk Score Stratifies Risk of Glaucoma Diagnosis and Severity in Eyes with Pseudoexfoliation. *Ophthalmology*. 2025 Aug;132(8):878-887. doi: 10.1016/j.ophtha.2025.02.013. Epub 2025 Feb 24. PMID: 40010646.

Presentations

Georgina Maxwell. *An Underrecognised Cause of Juvenile Open-Angle Glaucoma.* The Royal Australian and New Zealand College of Ophthalmologists 56th Annual Scientific Congress 14 NOV – 17 NOV 2025 Melbourne, Australia. FOXC1 Duplications:

Dr Antonia Kolovos. *Low polygenic risk scores identify individuals at minimal risk for primary open angle glaucoma.* The Royal Australian and New Zealand College of Ophthalmologists 56th Annual Scientific Congress 14 NOV – 17 NOV 2025 Melbourne, Australia.

Prof Jamie Craig. *A markedly improved glaucoma polygenic risk score enables strong clinical utility and disease prediction in all major ancestries – AVR Notable abstract.* The Royal Australian and New Zealand College of Ophthalmologists 56th Annual Scientific Congress 14 NOV – 17 NOV 2025 Melbourne, Australia

Dr Antonia Kolovos *A novel application of a primary open-angle glaucoma polygenic risk score determines likelihood of pigmentary glaucoma*. ARVO Annual Meeting, Salt Lake City, Utah, USA May 4-8, 2025

Australian Corneal Graft Registry (ACGR)

ACGR
AUSTRALIAN CORNEAL GRAFT REGISTRY

The Australian Corneal Graft Registry celebrated its 40th anniversary in May 2025 and registered graft number 50,000 in November. These grafts have been registered in almost 34,500 individual graft recipients, and follow-up has been received for over 41,000 (81%) grafts. A new record was set for total number of annual registrations, with 2,404 entered for grafts performed in 2024.

Just under 15,000 (29%) grafts continue to be followed, with an annual request for follow-up sent to surgeons in September. The longitudinal nature of the ACGR is one of its greatest strengths and 292 grafts have now been followed for more than 30 years, with 57 grafts stretching to over 35 years. We are pleased to have secured a further two years of funding through the Australian Government Organ and Tissue Authority (DonateLife), to fund the operations of the ACGR through to June 2027.

The ACGR released a new major report in June, which is freely available on the internet at: https://doi.org/10.25957/vfa8-8r43. This report examined outcomes from grafts registered with the ACGR to 30th June 2024 and included univariate and multivariable analyses. These were separated into cohorts of penetrating keratoplasties, Descemet's stripping (automated) endothelial keratoplasties, Descemet's membrane endothelial keratoplasties, deep anterior lamellar keratoplasties, and traditional lamellar keratoplasties. Visual outcomes following these different types of graft, stratified by indication for graft, were also reported.


THE AUSTRALIAN
CORNEAL GRAFT REGISTRY

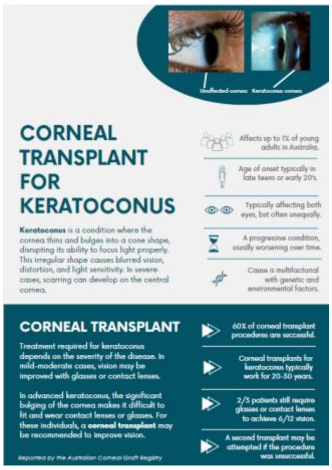
2025 REPORT

This report was published with assistance provided by The Australian Government Organ and Tissue Authority (DonateLife)

Two annual reports were produced in 2025. An interim report to contributors was presented at the annual Australia and New Zealand Corneal Society Meeting which was held online, due to cyclone Alfred disrupting the in-person meeting in Brisbane in March. A further written report, summarising the data contained in the ACGR database as of 30th June 2025, was produced in September. Both reports are available to all interested parties, online at: https://www.flinders.edu.au/fhmri-eye-vision/corneal-graft-registry.

The Consumer Friendly Information (COFI) project, which we commenced working on with SAHMRI Registry Centre staff and other member registries in 2024, was completed in 2025. The resulting information booklet and short animated video about corneal grafting for keratoconus were shared with the ACGR Community Engagement Group in November. We had positive feedback and enthusiasm from group members, including plans to share these resources within members' social circles.

Information booklet



CORNEAL TRANSPLANT FOR KERATOCONUS

Keratoconus is a condition where the cornea thins and bulges into a cone shape, disrupting its ability to focus light properly. This irregular shape causes blurred vision, distortion, and light sensitivity. In severe cases, scarring can develop on the central cornea.

Affects up to 1% of young adults in Australia.

Age of onset typically in late teens or early 20's.

Typically affecting both eyes, but often unequally.

A progressive condition, usually worsening over time.

Cause is multifactorial with genetic and environmental factors.

CORNEAL TRANSPLANT

Treatment required for keratoconus depends on the severity of the disease. In mild-moderate cases, vision may be improved with glasses or contact lenses.

In advanced keratoconus, the significant bulging of the cornea makes it difficult to fit and wear contact lenses or glasses. For these individuals, a **corneal transplant** may be recommended to improve vision.

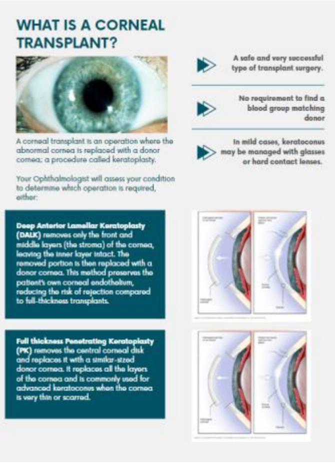
60% of corneal transplant procedures are successful.

Corneal transplants for keratoconus typically work for 20-30 years.

2/3 patients still require glasses or contact lenses to achieve 6/12 vision.

A second transplant may be attempted if the procedure was unsuccessful.

Reported by the Australian Corneal Graft Registry


WHAT IS A CORNEAL TRANSPLANT?

A corneal transplant is an operation where the abnormal cornea is replaced with a donor cornea; a procedure called keratoplasty.

Your Ophthalmologist will assess your condition to determine which operation is required, either:

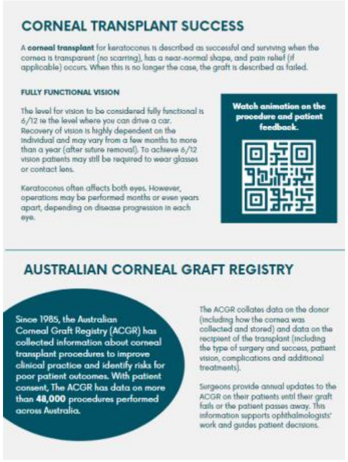
Deep Anterior Lamellar Keratoplasty (DALK) removes only the front and middle layers (the stroma) of the cornea, leaving the inner layer intact. The removed portion is then replaced with a donor cornea. This method preserves the patient's own corneal endothelium, reducing the risk of rejection compared to full-thickness transplants.

Full thickness Penetrating Keratoplasty (PK) removes the central corneal disk and replaces it with a similar-sized donor cornea. It replaces all the layers of the cornea and is commonly used for advanced keratoconus when the cornea is very thin or scarred.

A safe and very successful type of transplant surgery.

No requirement to find a blood group matching donor

In mild cases, keratoconus may be managed with glasses or hard contact lenses.


CORNEAL TRANSPLANT SUCCESS

A **corneal transplant** for keratoconus is described as successful and surviving when the cornea is transparent (no scarring), has a near-normal shape, and pain relief (if applicable) occurs. When this is no longer the case, the graft is described as failed.

FULLY FUNCTIONAL VISION

The level for vision to be considered fully functional is 6/12 ie the level where you can drive a car. Recovery of vision is highly dependent on the individual and may vary from a few months to more than a year (after suture removal). To achieve 6/12 vision patients may still be required to wear glasses or contact lens.

Keratoconus often affects both eyes. However, operations may be performed months or even years apart, depending on disease progression in each eye.

Watch animation on the procedure and patient feedback.

AUSTRALIAN CORNEAL GRAFT REGISTRY

Since 1985, the Australian Corneal Graft Registry (ACGR) has collected information about corneal transplant procedures to improve clinical practice and identify risks for poor patient outcomes. With patient consent, The ACGR has data on more than **48,000** procedures performed across Australia.

The ACGR collates data on the donor (including how the cornea was collected and stored) and data on the recipient of the transplant (including the type of surgery and success, patient vision, complications and additional treatments).

Surgeons provide annual updates to the ACGR on their patients until their graft fails or the patient passes away. This information supports ophthalmologists' work and guides patient decisions.


RECOVERY PROCESS AFTER YOUR TRANSPLANT

The initial recovery period after a corneal transplant is between one and three weeks, and you will require regular follow-up appointments for the first few months. Some patients will require suture removal and adjustment at 12 months.

Your Ophthalmologist will advise medication requirements, how to care for your eye and signs of complications. Due to the nature of the surgery, annual eye examinations are likely.

You may need to abstain from work, driving, lifting or certain exercises for a period. Please discuss return times with your surgeon.

Long term being mindful of your transplant is important to ensure the health of your eye and the vision you have achieved.

RISKS

While a corneal transplant is the safest type of transplant surgery, it does carry a small risk of complications, including:

- Rejection of the donor cornea
- Eye infection
- Glaucoma
- Suture issues
- Bleeding
- Cataracts
- Retinal problems
- Graft failure

It is important to discuss these risks with your Eye Specialist to aid in decision making.

THE IMPORTANCE OF DONORS

Corneal transplants are not possible without donors. It is encouraged that transplant recipients provide an anonymous thank you note to the donor's family in recognition of the wonderful gift of sight. For more information on organ donation visit donatelife.gov.au.

Australian Government
Organ and Tissue Authority

[Animated video Corneal Grafting for Keratoconus](#)

Lily Registry

The Lily Registry is a clinical quality registry monitoring outcomes for patients with eating disorders who require hospitalisation for medical instability. Established in 2022 by South Australian clinicians, it now supports services across multiple South Australian sites and provides structured feedback on medical stabilisation, nutritional care and multidisciplinary team processes.

In 2024, the Registry consolidated its role as core quality infrastructure for participating hospitals, with more than 90 consented paediatric and adult patients contributing over 160 admissions across two metropolitan sites. Regular dashboard reports summarise admissions, discharges and consent activity, supporting high consent rates and strong engagement from clinical teams.

A major focus has been using registry data to drive earlier access to nutritional expertise and essential therapy. Participating teams receive comparative data on time from admission to dietetics consultation and time from decision to commence enteric feeding to feeding initiation (“time-to-drip”), highlighting variation, prompting pathway review and helping address modifiable delays through clearer protocols and streamlined processes.

In 2026, the Registry will expand by onboarding Flinders Medical Centre and Lyell McEwin Hospital and will further embed its measures into routine clinical governance. Planned work includes a registry nested trial of a novel biomarker for meal compliance, health economics analyses pre and post registry implementation, and national collaboration through the TrEAT registry network to support comparative effectiveness analyses.

Kidney Health Registry

It has been almost five years since the establishment of the Kidney Health Registry based at Flinders Medical Centre jointly funded by the Departments of Nephrology and Urology at the Southern Adelaide Local Health Network (SALHN).

The registry which was created to monitor the long-term clinical outcomes of nephrectomy and non-surgical management of small renal masses and complex cysts including the quality of life of the participants, now has data relating to more than 1,100 patients treated in Flinders Medical Centre, Noarlunga Hospital or Repatriation General Hospital since 2005. In 2025, the Urology Department at North Adelaide Local Health Network (NALHN) joined as an additional site for recruitment.

This year our project: ‘Development of a score to predict risk of developing chronic kidney disease or worsening of pre-existing chronic kidney disease post-nephrectomy’ which was funded by the Flinders Foundation has been completed. Additionally, two other research projects “Assessing the outcomes of active surveillance vs nephrectomy in managing small renal masses” and “Different methods of assessing complex renal cysts” were successfully completed. The outcomes of all three projects are currently being prepared for publication. An additional article is currently under review. We presented these studies at the Urology state meeting and at the SALHN research week and won two outstanding presentation awards during the SALHN research week.

The registry continues to pursue its aim in helping clinicians and patients in making informed treatment decisions upon diagnosis of kidney cancer and to improve the care of these patients especially post nephrectomy. Our long-term goal is to expand to other health networks across the state and country.

MYelopathy NAtural History (MYNAH) Registry

The MYelopathy NAtural History (MYNAH) Registry, under Spine Labs led by CI Professor Ashish D. Diwan and co-CI Dr Nashwa Najib, is dedicated to advancing spinal health for Australians with non-traumatic spinal cord injuries. Established in December 2022 (ACSQHC-ARCR-258, UNSW iRECS3634, CALHN ref 21759), it is the world's first registry to explore the natural history and biological basis of degenerative cervical myelopathy. Patients are enrolled from 13 sites via an opt-in approach, irrespective of surgical status, enabling longitudinal tracking of disease progression through six-monthly PROMs. A dedicated biobank stores plasma and serum samples for biomarker research using proteomics and AI-driven bioinformatics.

In early 2025, Spine Labs expanded from UNSW to the University of Adelaide, marking a major growth milestone. Since then, extensive engagement has occurred with the University of Adelaide, Royal Adelaide Hospital, Women and Children's Health Network, SAHMRI, and the SA Minister for Health. As part of scaling to South Australia, Northern Territory, and Western Australia, Professor Diwan's team relocated to Adelaide. Governance approval through the CALHN ethics and governance office has enabled commencement at the Royal Adelaide Hospital. Additionally, collaborations with New Zealand researchers are strengthening global partnerships and impact.

Publications

The registry's work has already produced four high-impact publications, reinforcing its role in advancing spinal research and clinical practice:

Najib, N., Sial, A., Bohra, H., and Diwan, A.D. (2025), MYNAH Registry: A novel approach to decoding the natural history of degenerative cervical myelopathy. *Journal of Clinical Orthopaedics and Trauma.* https://doi.org/10.1016/j.jcot.2025.103075

Najib, N., Yataganbaba, A., Briggs, N.E., Ghahreman, A., Mobbs, R., Rao, P.J., Hansen, M., Davies, M., Kohan, S., Kulkarni, V., Sial, A., Ambikaipalan, A. and Diwan, A.D. (2024), Baseline characteristics of patients with degenerative cervical myelopathy in Australia: analysis from the MYelopathy NAtural History registry. *ANZ Journal of Surgery*. https://doi.org/10.1111/ans.19354

Wasinger, V. C., Bustamante, S., Najib, N., Diwan, A., Jayasena, T., Chowdhury, N. S., Beretov, J., & Schabrun, S. (2025). Enzymes Drive Glutathione Shunt to Explain Oxidative State Using an In-Parallel Multi-Omic Method. *International Journal of Molecular Sciences*, 26(8), 3632. https://doi.org/10.3390/ijms26083632

Chauhan, R. V., Segar, A. H., Diwan, A. D., Najib, N., Zeng, I., Rice, D., & White, S. G. (2025). Diagnostic and Surgical Decision-Making for Degenerative Cervical Myelopathy: A Survey With Post-Stratification Analysis. *Global Spine Journal.* 2025;0(0). doi:10.1177/21925682251388910

Staff feature: Nashwa Najib

Nashwa recently relocated from Sydney to Adelaide to lead the scale-up and capacity-building for the Registry. As part of this initiative, she has submitted a CQR capacity-building grant and successfully obtained governance approvals from Central Adelaide Local Health Network (CALHN).

The MYNAH Registry was originally established as part of her PhD project and has already identified unique blood signatures through proteomics, which hold promise for developing a diagnostic blood test to enable early detection of degenerative cervical myelopathy. In addition, Nashwa is working on integrating hospital EMR data into a new registry platform to support robust benchmarking and reporting.

Nashwa is the CEO, MYNAH Registry. She is awaiting the outcome of her PhD (Spinal Medicine) and in 2026 will commence a role as a Medical Scientist (L3) at CALHN, her qualifications include MBBS and MPhil (Medicine).

PRODUCT REGISTRIES

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

Australian Transcatheter Valve Therapies Registry (ATVT-R)

The Australian Transcatheter Valve Therapies Registry (ATVT-R) is a clinical quality registry supported by the Australasian Cardiac Outcomes Registry (ACOR) Ltd to monitor procedural and clinical outcomes of patients undergoing cardiac valve procedures for the entire Australian population and inform on device safety.

Highlights of 2025

- Previously focused solely on transcatheter aortic valve implantations and known as the TAVI Registry, the registry was expanded and renamed in 2025 to the ATVT Registry to include data collection for all four cardiac valve procedures— aortic, mitral, pulmonary and tricuspid.
- ATVT-R (previously TAVI-R) has now collected over 30,000 cases since commencement of the Registry.
- Continues to inform stakeholders by reporting bi-annually to individual sites, operators and device companies.
- Disseminated TAVI consumer information to sites prepared in collaboration with the SAHMRI Registry Centre as part of the Consumer-Friendly Information (CoFI project) funded by the Department of Health and Aged Care (Health/E23-209685)
- Ethics approval has been obtained for TAVI data to be linked with the AIHW National Death Index.

Publication

Sinhal A, Bennetts J, Bhindi R, Cashman K, Deakin A, Gooley R, Heath E, Lorimer M, Muller D, Ng M, Roberts-Thomson R, Walters D, Walton A, Whitbourn R, Wilson W, Yong G, Camuglia A. Australian Cardiac Outcomes Registry of Transcatheter Aortic Valve Implantation: Report and Update of Transcatheter Aortic Valve Implantation in Australia. *Heart Lung Circ*. 2025 May;34(5):472-484. doi: 10.1016/j.hlc.2025.02.107. Epub 2025 Mar 18. PMID: 40102102.

Collaboration

The ATVT-R is:

- a member of the SAHMRI Registry Centre Advisory Committee, and
- ACOR ATVT-R Steering Committee and Working Group.

Dental Implant Registry (DIR)

The Dental Implant Registry (DIR) is a non-for-profit registry supporting safer, higher-quality, evidence-informed dental implant care to improve patient outcomes. DIR collects and analyses routine clinical data on implant components, procedures, and outcomes, and is being developed in alignment with **Clinical Quality Registry (CQR)** principles and national best-practice frameworks. In Australia, dental implants are regulated by the **Therapeutic Goods Administration (TGA)** and classified as **Class IIb medical devices** (moderate to high risk).

DIR supports quality improvement by identifying outcome trends and potential risk factors, strengthening collaboration across clinicians, researchers, industry, and regulators, and building an evidence base for safer care, greater consistency, and future benchmarking and routine reporting. In **2025**, the registry recorded **9,617 registrations** across **4,842 patients**.

Key highlights (2025)

- **First peer-reviewed publication milestone:** DIR received confirmation that its first collaborative journal article will be published. **Authors:** Dr Steven Soukoulis (DIR Chief Investigator), Emeritus Professor Alastair Goss (DIR Research Advisor), and Dr Scott Davis (DIR Scientific Committee) This marks an important step in translating registry activity into peer-reviewed evidence.
- **Education and awareness:** Delivered DIR's first webinar, (April 2025), sharing early learnings and building awareness of registry science in implant dentistry.
- **Early dissemination of insights:** Shared early registry insights through conference engagement and presentations during 2025.
- **Ethics approval to operate as an Opt-Out Registry**: DIR received ethics approval to operate as an opt-out registry, enabling streamlined practice participation and reducing administrative burden for clinicians while maintaining transparency for patients.
- **Capability strengthening:** Continued refinement of systems and workflows to improve data completeness and quality, and preparedness for further reporting development as the registry matures.

Industry events attended and engagement (2025)

- **Arab Health / Global Healthcare Medical Expo** (Engagement/meetings) Dubai, UAE Jan 2025
- **DIR Webinar (Online)** - April 2025 *"From Register to Registry", Chair: Emeritus Professor Alastair Goss, DIR Research Advisor.*
- **ANZAOMS ASM** (**Adelaide, SA)** - November 2025 *"Early findings from the Dental Implant Registry", Presentation - Dr Steven Soukoulis, DIR Chief Investigator.*

St. Vincent’s Melbourne Arthroplasty (SMART) Registry

The St Vincent’s Melbourne Arthroplasty Outcomes (SMART) Registry is an institutional clinical registry housed at a tertiary referral hospital in Australia. The SMART Registry has been established to capture a broad range of longitudinal clinical and patient-reported outcome data to facilitate collaborative research that will improve policy and practice relevant to arthroplasty surgery for people with advanced arthritis of the hip or knee.

As of 31 December 2025, The SMART Registry houses clinical and patient reported outcome data on 17,450 arthroplasty procedures performed in 13,343 patients, with 543 procedures in 507 patients added in 2025. Patients are followed out to 20 years with over 156,000 patient surveys recorded in the Registry. SMART also undergoes annual linkage with the AIHW MBS & PBS data. To date nine PhD candidates have utilized Registry data for their Thesis and there have been a total of 64 peer reviewed publications arising from SMART data.

Highlights for 2025 include completion/graduation of two PhD candidates and three peer reviewed publications.

PhDs

- Dr Siddharth Rel, MD-PhD: Cost effectiveness of reducing length of stay for total joint arthroplasty.
- Dr Cade Shadbolit, PhD: Association Between Central Nervous System Active Medication Use and Total Hip and Knee Arthroplasty Outcomes.

Publications

Rele S, Schilling C, Shadbolt C, Spelman T, Taylor NF, Dowsey MM, Choong PFM. Clinical and cost-effectiveness of earlier discharge from acute hospital after total joint arthroplasty. *ANZ J Surg.* 2025;95(1-2):180-8.

Rele S, Shadbolt C, Schilling C, Thuraisingam S, Trieu J, Choong ELP, Gould D, Taylor NF, Dowsey MM, Choong PFM. Validation of the Clavien-Dindo classification and Comprehensive Complication Index as measures of morbidity following total hip and knee arthroplasty. *Bone Joint J*. 2025;107-B(1):81-8.

Shadbolt C, Schilling C, Inacio MC, Thuraisingam S, Rele S, Castle DJ, Choong PFM, Dowsey MM. Association Between Pharmacologic Treatment of Depression and Patient-Reported Outcomes Following Total Hip and Knee Arthroplasty. *J Arthroplasty*. 2025;40(1):53-60 e4.

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