SAHMRI
South Australian Health & Medical Research Institute

SAHMRI
Registry
Centre

Annual Report 2024

Letter from the Chief Operating Officer & Director, Health Policy Centre

The SAHMRI Registry Centre unites SAHMR-based registries with others throughout South Australia and nationally. It is a centre of excellence for registries and registry science that provides a unique point of difference striving to ensure the registries are optimally utilised by policy makers, health services and researchers across South Australia and nationally.

Funding from the Australian Government Department of Health and Aged Care, under the National Clinical Quality Registry (CQR) Program, supports several projects being undertaken by the Registry Centre with a central focus on promoting best practice and communicating health outcomes to the public.

There is much to expect from our Centre over the next few years as the model of centralised project management develops further and the Centre's educational activities continue to grow, develop and contribute to the evolution of the workforce in the CQR Sector.

In 2024, the Centre welcomed two new registries to the collaboration; the Coronary Angiogram Database of SA (CADOSA) and Lily, the Eating Disorder Registry. At the time of writing this letter, several other registries have also expressed their interest in joining the Centre. As more registries join the Centre and become more connected in the sector, there is greater opportunity for the sharing of knowledge and experience as all members move towards greater alignment with the Australian Commission on Safety and Quality in Health Care's CQR Framework.

The collaboration and partnerships with key stakeholders at both federal and state level are developing and contributing to a national approach as the profile, value and impact of clinical quality registries on health outcomes are more readily recognised.

I would like to extend my appreciation to the executive team; Strategic Director Cindy Turner and Academic Leads Professor Maria Inacio and Professor Stephen Mc Donald, for their leadership, strategic vision and commitment to driving the success of the Centre. I would also like to take this opportunity to acknowledge the team whose hard work is contributing to activities to support and expand national best practice in registry science and demonstrate the value of registries.

I look forward to continuing to support the SAHMRI Registry Centre as it continues to influence the development of registry science in Australia.

Professor Caroline Miller

Director SAHMRI Health Policy Centre
Chair, SAHMRI Registry Centre Advisory Group

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Letter from the SAHMRI Registry Centre Strategic Director

I am pleased to present the third SAHMRI Registry Centre Annual Report. In 2024, funding from the Australian Government Department of Health and Aged Care (the Department), under the National Clinical Quality (CQR) Registry Program saw the Centre successfully implement our model of project delivery through centralised project management. This enabled us to welcome new additions to our team and to support Centre members to expand and enhance best practices in registry science while driving innovation and development across the 24 member registries and the broader CQR sector where appropriate.

The projects we are delivering, funded by the Department, are important activities to support the implementation of the Australian Framework for National Clinical Quality Registries 2024[1] across our member registries. These projects have enabled the Centre to continue developing a shared learning environment and deliver quality educational opportunities that build capacity within the CQR sector (outlined in more detail in the Centre Activities on page 6).

The team continues to contribute more broadly to the growing CQR sector:

Australian Registry Annual Scientific Meeting 2024

As part of the Organising Committee, we contributed to a successful Australian Registry Symposium, which was held from the 3-5 December 2024 at the Pullman Melbourne Albert Park. This year the event was combined with the Australian Clinical Trials Alliance (ACTA) as the 2024 Clinical Trials and Registries Symposium. The program included a full day Clinical Registry Symposium and a full day of Clinical Registry workshops. I was fortunate to have the opportunity to present on the work of the CQR Advisory Service Pilot and our team hosted three of the four workshops.

CQR Communication and Collaboration Hub

The Hub is a partnership between Monash University, SAHMRI and ACTA, supported by the Department's CQR program. In 2024 the Hub delivered programs across four key areas:

- *Professional Development Program* – This program includes the Australian Registry Symposium (as above), the SAHMRI Registry Centre Symposium and two Registry Special Interest Group (SIG) webinars
- *CQR Communication and Collaboration* – I have appreciated being part of the editorial committee for the Benchmark quarterly newsletter, which continues to provide an avenue for sector communication
- *Resources Development* – There has been enormous progress on the development of the Good CQR Practice Guide, led by Susannah Ahern (Monash University) and it has been valuable to be part of the project team. I look forward to continuing this involvement in 2025, developing of the online Training Module to accompany the Guide.
- *Promotion of Registry Science* – The Registry Centre will continue to contribute to the promotion of registry science through all opportunities presented to us.

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[1] Australian Commission on Safety and Quality in Health Care. *Australia Framework for National Clinical Quality Registries 2024*. Sydney; ACSQHC, 2024.

CQR Sector Development

In this time of development and review of the CQR sector, where we are providing guidance[1] on many aspects of CQRs such as governance, systems, reporting and data driven improvements, it is timely to reflect on how we inform the delivery of equitable health care and outcomes across Australia. The role of registries is to monitor and report, informing policy development and service delivery change for improved outcomes. The survey conducted as part of the environmental scan of member registries (funded by the Department) shows us that most member registries (n=17, 85%) collect Aboriginal and Torres Strait Islander identifiers. Of these, only two registries meet all aspects of data sovereignty, governance and reporting.

Only seven (35%) member registries have a mechanism in place to ensure the priorities of different cohorts, including women, regional/remote, people with a disability, socio-economically disadvantaged groups and culturally and linguistic diverse communities are considered in the collection, monitoring, reporting and use of the data. Of these, only two registries produce an equitable healthcare outcome report.

As we go forward and encourage registries to more closely align themselves with the Strategy and the Framework these are important factors for all registries to consider.

Cindy Turner

Strategic Director
SAHMRI Registry Centre

Introduction

Purpose

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

Aims

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

Governance

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

The Centre has now moved to a model of project delivery through centralised project management. This model uses our expertise to expand and enhance best practices in registry science and drive innovation and development across the 24 Centre member registries (and the broader CQR Sector when appropriate) through the delivery of specified projects. Current projects are funded by the Australian Government Department of Health and Aged Care (the Department), National CQR Program.

The SAHMRI Registry Centre Executive Group

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

- Professor Caroline Miller - SAHMRI Chief Operating Officer and Director Health Policy Centre at SAHMRI
- Cindy Turner, Strategic Director SAHMRI Registry Centre
- Professor Maria Inacio – Director ROSA and Joint Academic Lead of the SAHMRI Registry Centre
- Professor Stephen McDonald - Executive Director ANZDATA and Joint Academic Lead of the SAHMRI Registry Centre.

The SAHMRI Registry Centre Advisory Group

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

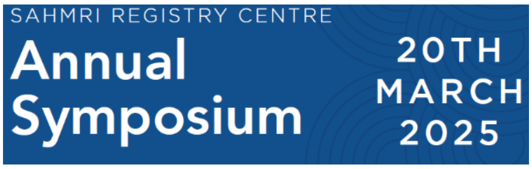
Advisory Group Members

Chair: Prof Caroline Miller	SAHMRI
Cindy Turner	SAHMRI Registry Centre
Prof Maria Inacio	ROSA
Prof Stephen McDonald /Kylie Hurst	ANZDATA, ANZOD, ANZETD, ANZLKD ANZHTR, ANZLUNG
Anita Deakin/ Michelle Lorimer	TAVI Registry
Kelly Skelton	ASPIRE
Prof Kerryn Williams / Dr Miriam Keane	ACGR
Dr Steve Soukoulis	DIR
Dr Catherine Gibson / Heather Scott	SABDR, SACPR
Dr Michael O'Callaghan	SA-PCCOC
Karen Hall	ANZRAG
Helena Kopunic	ANZASM, BQA, ANZELA-QI
Prof Justine Smith	IVRLR
Dr Jessica Orchard	ARENA
A/Prof Jordan Li / Sarah Bodda	Kidney Health Registry
Prof Richard Kitching	ANZVASC-QDR
Dr Patrick Russel	LILY (Eating disorders)
A/Prof Rosanna Tavella	CADOSA
Stephanie Flak	Wellbeing SA
Professor David Roder	Cancer Population Registries

**Representatives may change throughout the year*

Registry Centre Activities

2025 Registry Centre Annual Scientific Symposium



The Registry Centre is busy planning the Annual Scientific Symposium for 2025 to be held on March 20, with a theme of: Advancing Healthcare Through Registry Data & Analytical Insights.

We are delighted to have:

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

As per previous years, the release of this report will coincide with the Annual Symposium.

2025 SAHMRI Registry Centre Inaugural Datathon

In addition to the full day symposium, this year the Centre is hosting our Inaugural Datathon. The Datathon is a collaboration with the Australia and New Zealand Intensive Care Society (ANZICS) Registry, the Australian & New Zealand Dialysis and Renal Transplant Registry (ANZDATA) and the Registry of Senior Australians (ROSA). The Datathon is an interactive event with up to 60 like-minded participants who will work together in teams to solve a clinical question through applying data science tools and analytical techniques using health datasets.

2024 Registry Centre Seminar/Workshops

Seminar #1: Canadian Network for Observational Drug Effect Studies (CNODES): using distributed data networks to improve drug safety and effectiveness

Guest speaker: Professor Ingrid Sketris - Professor of the College of Pharmacy, Dalhousie University. With a focus on health services, policy, knowledge translation and pharmacoepidemiology, her research involves identifying gaps in appropriate drug use and evaluating strategies to improve these. Prof Sketris is the Knowledge Translation team lead for CNODES. Prof Sketris is a Visiting Research Fellow at UniSA Allied Health and Human Performance throughout February 2024.

Seminar #2: Fundamentals of Impact Workshop

Presented by: Dr Tamika Heiden, Research Impact Academy.
Participants had the opportunity to explore:

- The fundamentals of impact including impact types and indicators
- How to identify indicators of successful uptake of outputs from the registry
- The different ways of capturing the impact from your registry
- How to communicate impact and value.

Seminar #3: Framework Reporting


AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

Australian Framework for National Clinical Quality Registries 2024

August 2024

Timely data analysis and reporting, accompanied by clinical interpretations, play a critical role in safety and quality improvement and are core functions of a CQR. This workshop led the participants through a process to assess gaps in current reporting for their registry against the Framework.

When asked about factors that prevent their registry from providing best practice reporting, five participants reported that 'resource[s]' were a gap or factor that prevented their registry from providing best practice reporting. The types of resource challenges were also indicated by other participants who highlighted a lack of funding, as well as expertise such as 'biostatisticians' and 'admin support'. Other factors included 'mandatory participation', 'poor participation' and 'case ascertainment'.

Participants indicated that they believed the skills and knowledge of statisticians or biostatisticians, could be shared amongst registries.

Discussion among participants indicated that there was benefit in exploring other areas of the Framework, this is something the Centre will consider for future seminars.

Statistical Education Forums

There were eight sessions of the SAHMRI Statistics Education Forum in 2024 with attendance averaging 18 participants across the sessions. There were six presentations of biostatistical research and two journal article discussions. Presenters included statisticians from the ANZDATA, AOANJRR and ROSA Registries. 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

Consumer Engagement

In addition to the Consumer Information (CoFI) project which directly works with consumers, the Centre continues to be part of the online Consumer Engagement Community of Practice (CoP) coordinated by Health Translation SA (HTSA). Involvement in the CoP will not only strengthen our work on the newly funded Consumer Friendly Information (CoFI) project but provides an avenue for member registries to connect with others working with consumer groups.

Project Report from the Senior Project Manager

This report presents the activities of the Registry Centre over the last 12 months and importantly reports on a new era for the Registry Centre as we embark on important projects designed to support the implementation of the Framework. In particular, the CQR Advisory Service pilot, has been an important development, the potential to transform the existing support into a more sustainable service is being explored.

Commencing January 2024 and due for completion June 2025, the Registry Centre is leading a series of five activities to support and expand national best practice in registry science and demonstrate the value of registries. This work is supported through the National Clinical Quality Registry Program, Australian Government Department of Health and Aged Care (the Department).

The project team involved in these activities include:
- Cindy Turner, Strategic Director
- Tamara Hooper, Senior Project Manager
- Sarah Eley, Senior Project Officer (CoFI Project)
- Elsie Nunu, Project Officer
- Hannah Freeman, Project Officer

Incorporating the Australian Framework for National CQR (2024)[1] and the National Strategy Priorities[2] the five activities include:
1. **Consumer Friendly Information (CoFI)** – Translating registry outputs into consumer-friendly resources, through co-design with the community.
2. **Public Reporting** - To increase best practice public reporting across registries.
3. **Advisory Service** - To pilot a CQR Advisory Service that leverages the expertise within the SAHMRI Registry Centre, and test transforming this function into an ongoing, sustainable service.
4. **Value & Impact** - To develop an evaluation framework to demonstrate the value and impact of member registries and compile a series of case studies.
5. **Data Linkage** – To describe linkage activities and experiences of Registry Centre members and develop high level recommendations for best practices.

Consumer Friendly Information (CoFI)

Registries collect vast amounts of valuable health information that could guide patient decision making. However, registry outputs are not usually created for and shared with the community. Through a co-design process with the *CoFI Consumer Group*, the Registry Centre is transforming registry outputs into accessible resources that empower the community to make informed healthcare decisions. These resources will be widely shared in locations identified by consumers as relevant and accessible. Additionally, the project will develop a series of guides to support registries in adapting their own outputs for consumer use. This initiative is being carried out in collaboration with three SAHMRI Registry Centre members: the Registry of Senior Australians (ROSA), the Transcatheter Aortic Valve Implantation Registry (TAVI), and the Australian Corneal Graft Registry (ACGR).

Public Reporting

The Registry Centre is working to improve public reporting across its member registries and translate findings into a set of public-facing best practice resources. Increased public access to CQR data forms part of Strategy[2] Pillar 5: Priority 20 with guidance for the provision of CQR reports being an integral component of the Framework[1] released mid-2024. Reporting practices, recommendations and strategies to increase

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[2] Australian Government Department of Health and Aged Care. *A National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030.* Canberra: Department of Health; 12 Feb 2021, updated 24 Jul 2023. https://www.health.gov.au/resources/publications/a-national-strategy-for-clinical-quality-registries-and-virtual-registries-2020-2030 (accessed October 2024)

public reporting have been provided to participating registries for consideration. In addition, the findings from this project will inform recommendations provided to the Department of Health and Aged Care CQR Program.

CQR Advisory Service Pilot

Increasing communication and collaboration within the CQR sector forms part of Strategy[2] Pillar 3: Priority 15. As part of the broader work on a CQR Communication and Collaboration Hub, the Registry Centre has been piloting a CQR Advisory Service whereby advice and guidance is provided in the following areas:

- Establishment of a new CQR
- Support regarding further development of existing registries seeking to move their registry closer to meeting the requirements of the Framework[1]
- CQRs seeking to undertake more advanced activities such as registry nested trials, data linkage studies, international collaborations and comparisons, strategic planning, audit review.

To further support the advice, a number of documents and guides have been developed and will be available for use by the CQR sector at the end of the pilot. The pilot highlighted the critical need for a national service. Recommendations developed in collaboration with members of the broader CQR sector will inform requirements for a future sustainable national service. The recommendations will be included in the final project report provided as part of the Department's National CQR Program.

The CQR Advisory Service can be contacted on registrycentre@sahmri.com or by speaking directly to the Strategic Director, Cindy Turner (08) 8128 4281.

Value & Impact

Demonstrating impact is becoming increasingly important for registries i.e. ongoing and future funding, contribution to research, ensuring registry relevance and reporting to funders and other stakeholders. Assessing contributions which CQRs make to improvements in clinical practice and patient outcomes, forms part of Strategy[2] Pillar 2: Priority 9 and Strategy[2] and Pillar 4: Priority 18.

The early learnings from this project highlighted a gap in participant knowledge and understanding of registry impact particularly when asked to provide evidence of the impact from their registries. Participants have varying different levels of familiarity with identifying, measuring, evaluating and demonstrating impact. Several different strategies were applied to assist in closing this gap: interactive style workshops, the development of a guide to demonstrating impact and individual member meetings to identify impacts and determine examples which would be suitable for case study publications. A collation of case studies that measure the value and impact of Registry Centre members will be available at the end of June 2025.

Data Linkage

Facilitating strategic data linkage projects between CQRs and administrative data forms part of Strategy[2] Pillar 6: Priority 22. The Registry Centre is leveraging the experiences and lessons learnt from their multiple member registries. In partnership with the Registry of Senior Australians, a practical guide for data linkage will be available mid-2025.

Tamara Hooper

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[1] Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries 2024.* Sydney: ACSQHC, 2024. https://www.safetyandquality.gov.au/publications-and-resources/resource-library/australian-framework-national-clinical-quality-registries-2024 (accessed October 2024)

[2] Australian Government Department of Health and Aged Care. *A National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030.* Canberra: Department of Health; 12 Feb 2021, updated 24 Jul 2023. https://www.health.gov.au/resources/publications/a-national-strategy-for-clinical-quality-registries-and-virtual-registries-2020-2030 (accessed October 2024

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 Andiogram Database of South Australia **(CADOSA)**

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

PRODUCT REGISTRIES

Transcatheter Aortic Valve Implantation **(TAVI)**
Dental Implant Registry **(DIR)**

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)**
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)**
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Australia & New Zealand Emergency Laparotomy Audit - Quality Improvement **(ANZELA-QI)**
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Australasian Registry of ECGs of National Athletes **(ARENA)**
BreastSurgANZ Quality Audit **(BQA)**
Coronary Andiogram Database of South Australia **(CADOSA)**

Registry of Senior Australians (ROSA)

The Registry of Senior Australians (ROSA) was established in 2017 to deliver evidence to improve the quality of ageing and aged care services delivered to older people in Australia. ROSA maintains an Australian Clinical Quality Registry and national data platform to achieve our mission of conducting innovative and translational research, aimed at understanding and improving the health, service utilisation, medication use, mortality, and other important outcomes of older people.

In July 2024, the ROSA Research Centre was formally established through our new partnership between SAHMRI and the Caring Futures Institute, College of Nursing and Health Sciences at Flinders University. Several notable research and policy translation achievements highlighting our focus on driving quality improvement efforts in the aged care sector continued this year including:

- Publication of 31 academic articles, delivered six academic, policy and aged care practice-related reports, developed 305 non-public, confidential reports for aged care providers in South Australia (208 for residential aged care facilities and 97 for home care service providers) and delivered 17 conference presentations (visit this link for a full list).

- National recognition from the Australian Government's Office of the Inspector-General of Aged Care in its report on the **'*Implementation of the Recommendations of the Royal Commission into Aged Care Quality and Safety*'** delivered to Government in June 2024. The Inspector-General's recommendation was '*that the government examine the potential of SAHMRI's work in a national context, and how it can be best supported to achieve its full potential*.' ROSA also received the **SAHMRI's Translation and Impact Award** for this work. This recognition is reflective of the culmination of ROSA's high quality research led by Professors Maria Inacio and Gillian Caughey and is a credit to the team's contributions.

- In July 2024, ROSA **announced our new partnership with Bolton Clarke**. Bolton Clarke is one of Australia's largest independent, not-for-profit aged care providers and joins the ROSA Steering Committee alongside Silverchain and ECH Inc. The Bolton Clarke team brings a wealth of experience and expertise in relation to delivering and conducting research focused on residential aged care, home care and retirement living.

- ROSA was awarded a $3 million grant from the Australian Government's Medical Research Future Fund National Critical Infrastructure grants (2024-29) led by Professors Maria Inacio and Gillian Caughey. This grant supports ROSA's collaboration with seven project partners to investigate impacts of workforce on quality of aged care. The Australian Ageing Agenda is our communication partner for this project, recently publishing an article summarising the project.

ROSA data platform update:

ROSA Prospective Cohort (SA only): Data updates were received in December 2024 and includes data from 2018-2023 for 66,400 aged care recipients in SA, to be used for our 2025 release of direct-to-provider ROSA Outcome Monitoring System reports.

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 linkages include the Australian Immunisation Register and national social welfare data (Data Over Multiple Individual Occurrences, DOMINO).

Australia & New Zealand Dialysis & Transplant Registry (ANZDATA)

ANZDATA continues to play an essential role in supporting the highest standard of kidney care in Australia and New Zealand. All renal units in Australia and New Zealand participate in the Registry, leading to complete coverage.

In 2024, ANZDATA has been instrumental in advancing research, fostering community engagement, and contributing to the body of knowledge in nephrology, as we continue to expand our research portfolio. The year achieved significant milestones for the ANZDATA Registry, here are our key highlights.

Key Achievements in 2024:

1. Haemodialysis Capacity Survey Special Report

A major highlight of 2024 was the ANZDATA & ANZSN Haemodialysis Capacity Survey Special Report. This project was conceived to address the sectors concerns about health services ability to meet the demand for dialysis, a critical life sustaining treatment. This report, based on a survey integrated with registry data collection, was presented at the Annual Scientific Meeting of the Australian and New Zealand Society of Nephrology (ANZSN).

Key findings included:

- Dialysis infrastructure concerns were previously anecdotal, but the report quantified haemodialysis capacity across jurisdictions and identified regional disparities
- Many dialysis units face staffing and funding shortages, leading to non-operational dialysis chairs
- Over 50% of units reported waiting lists for new patients, with public facilities experiencing greater pressures

This report, along with future ANZDATA surveys, will continue to inform clinicians, policymakers, health departments, advocacy groups, and the community about dialysis capacity and access issues.

2. Exploring Patient Travel

Using ANZDATA data and sophisticated geospatial models, we have performed analyses of travel time and distance between patients' residential postcodes and dialysis units, to characterise the burden of travel for patients and identify where patients are treated geographically in Australia. In 2024, we completed a geospatial analysis to describe variation in kidney replacement therapy patient incidence across Australia and over the last two decades, to determine the emergence of hotspots of incidence (https://doi.org/10.1016/j.anzjph.2024.100161). This work is being supported by four consumers from the ANZDATA Consumer Advisory Panel and Community Interest Register.

3. SWIFT Trial (Symptom Monitoring with Feedback Trial)

An investigator driven, registry-based trial, SWIFT focusing on improving quality of life and survival rates for dialysis patients through symptom monitoring and clinician feedback. The study achieved major milestones in 2024, including over 2082 participants recruited across 72 dialysis units in Australia and the first-ever clinical trial conducted in far-remote satellite units on Thursday Island and Bamaga (QLD). The SWIFT team has added collaboration with the Australian Teletrial Program (ATP) in SA and QLD to implement the Teletrial model within satellite units across both states.

4. Consumer-prioritised Research in Kidney Failure

Identifying key factors from the perspective of individuals with lived experience is a major body of work the Registry is supporting. This included in 2024, a consumer survey to understand priorities quality indicators in kidney failure care. ANZDATA in collaborative work with the BEAT-CKD network ended the year with a very successful education forum with over 100 people in attendance.

2024 was also the first full year for the ANZDATA Consumer Advisory Panel (CAP). During the year, the ANZDATA CAP co-chairs presented at the ANZSN Consumer and Carers Day, as well as the Annual Scientific meeting. The consumer and carers day was co-design with consumers and engaged over 67 registrations (46 onsite, 21 online).

Photo Right: Jasmin Mazis (Patient Engagement Officer), L Torrisi (ANZDATA CAP Co Chair) and S Shirley (ANZDATA CAP Chair) at ANZSN Conference in Adelaide (Kaurna Land) presenting a poster on 10-year PD trends.

5. The Pregnancy and Kidney Research (PKRA) website

(https://www.pkra.com.au/) was launched, marking a significant milestone in our efforts to raise awareness about kidney health and parenthood in Australia. Additionally, a consumer-led [Facebook group](), was established, further engaging with the community.

Throughout the year our dedicated team of consumers were honoured with the South Australian Health Medical Research Institute (SAHMRI) End of Year Award for Community Engagement in December 2024 for their outstanding involvement.

Photo Left: Prof Shilpa Jesudason and Jasmin Mazis awarded the SAHMRI Community Engagement Award

6. Transplant Epidemiology Group (TrEG)

This year, the Transplant Epidemiology Group (TrEG), based at ANZDATA, made significant progress in post-transplant outcomes, donor factors, prediction models, and health economics. The TrEG researchers have contributed extensively to the field through publications and awards.

Notably, Dr. Georgina Irish received the Early Career Research Award from the Transplantation Society of Australia and New Zealand, and Dr. Alessandra Orsillo was awarded the David Taverner Travelling Scholarship.

For more information, visit TrEG Australia or follow us on X (Twitter) or Bluesky: @TrEG_Australia

ANZDATA in 2025

In 2025, ANZDATA will continue assessing dialysis capacity with a focus on input from both individual dialysis units and the head of all renal units to better define and understand this demand.

ANZDATA will continue its work in 2025 with the Transplant Society of Australia in New Zealand in redesigning the kidney transplant allocation system.

ANZDATA in collaboration with the Australian and New Zealand Society of Nephrology will continue to expand its trainee support program to upskill trainees around Australia and New Zealand in epidemiology and statistical methods.

Additionally, ANZDATA remains dedicated to enhancing the Consumer Advisory Panel (CAP), ensuring that patient perspectives shape future research and healthcare improvements.

Australia & New Zealand Organ Donor Registry (ANZOD)

The Australia and New Zealand Organ Donation Registry (ANZOD) collects and reports on organ, eye, and tissue donation data. This comprehensive dataset forms the foundation for generating valuable statistics that benefit local, national, and global communities. Established in 1989, the Registry remains a vital source of information for clinicians, healthcare educators, researchers, epidemiologists, scientific studies, and the public.

In 2024, ANZOD continued its commitment to high-quality reporting by producing both monthly and annual reports. Notably, the annual report underwent a significant redesign by a professional graphic designer, resulting in a fresh, modernised appearance that enhances its accessibility and visual appeal.

The ANZOD working group has initiated an extensive planning and review process for the annual report. This effort focuses on integrating new data capture methods, updating terminology, and improving reporting accuracy. To support these enhancements, the working group will hold a two-day intensive workshop in March 2025. The outcomes of this workshop will directly inform updates to the 2025 annual report, scheduled for release in May 2025.

Donation Activity 2024

513	**1396**	**1458**	**1588**
Total Actual Deceased Organ Donors	Total Organ Transplant Recipients (from Deceased Donors)	Total Organ Transplantation Procedures (from Deceased Donors)	Total Organs Transplanted (from Deceased Donors)

Total Organs Transplanted by Deceased Donors 2024
Australia Deceased Donors

838	**268**	**129**	**304**	**48**	**1**
Kidney	Liver	Heart	Lung	Pancreas	Intestine

Australia & New Zealand Living Kidney Registry (ANZLKD)

The ANZLKD Registry, operating under the auspices of the ANZDATA Registry was established in 2004. This clinical quality registry monitors the safety of living kidney donation across Australia and New Zealand. The Australian and New Zealand community is an essential partner of living kidney donation. This is because living kidney donation only occurs through the support and goodwill of the community. Without a donor and their family willing to donate, many people who need a transplant will not receive one.

ANZ LKD
AUSTRALIA & NEW ZEALAND
LIVING KIDNEY DONATION REGISTRY

Data continues to be collected and reported back to the community and key stakeholders monthly. Statistics reported monthly are preliminary until the annual survey is complete and this data is reported in the ANZDATA Registry Annual Report in the Kidney Donation chapter. This chapter describes donor characteristics and reports on the number of living kidneys donated for the purpose of transplantation.

In 2024, there were 253 living kidney donors in Australia (9.3 dpmp), representing 24% of all kidney transplant operations. In New Zealand, the 83 (15.6 dpmp) living kidney donations, represented 42% of kidney transplants performed. The proportion of living donors from the kidney paired exchange program, which operates across the two countries, continues to be higher in New Zealand. However, genetically related donors to their recipient, remain the largest proportion of living kidney donors in Australia (116 donors). The number of ABO incompatible transplants continues to increase, and numbers have returned to those seen prior to the COVID-19 pandemic. Across both countries, women continue to make up the greater proportion of donors.

2024

336 Total Living kidney donors from Australia and New Zealand = **250** Living organ donors facilitated by individual transplant units + **86** Living organ donors through the ANZKX program

Australia	NSW	VIC	QLD	SA	WA	New Zealand
253	**89**	**77**	**26**	**33**	**28**	**83**

Note: Living kidney donations from ACT, NT and TAS take place in other states

ANZLKD is the mainstay for national data collection across both countries. Data is collected at the time of donation event and at annual anniversary follow up thereafter. There exists a comprehensive dataset with robust data collection processes at baseline, however challenges are evident in data capture post donation. For these very reasons the Living Kidney Donor Working Group re-established in 2024, to support the ANZLKD Registry in raising awareness and reporting on outcomes of living kidney donors following donation. Although challenges exist in long-term data collection of this population, the Registry aims to explore novel ways of data collection and expand the research with strong engagement from donors and donor families (consumers).

Australia & New Zealand Heart Transplant Registry (ANZHTR)

The Australia and New Zealand Heart Transplant Registry (ANZHTR) plays a critical role in tracking the number and outcomes of patients with advanced end-stage heart failure who are waitlisted for a heart transplant.

In recent years, ANZHTR has obtained ethics and governance endorsements across all Australian heart transplanting sites. This foundation ensures that data collection and reporting processes align with national and international best practices. Looking ahead to 2025, the Registry is set to focus on further strengthening data collection efforts and developing advanced reporting mechanisms to enhance transparency and clinical utility.

One of the most significant initiatives for 2025 will be the integration of historical heart transplant registry data dating back to 1984. This retrospective data compilation will provide a comprehensive, long-term perspective on heart transplantation trends, outcomes, and evolving clinical practices. The first ANZHTR annual report will be designed to leverage this extensive longitudinal dataset, offering in-depth insights that will support clinical decision-making and policy development.

ANZHTR is also committed to re-establishing Australia's contribution to the International Thoracic Organ Transplant (TTX) Registry. After a hiatus since 2018, renewed participation in this global initiative will ensure that Australian data is represented in international research and benchmarking efforts. By sharing data with the TTX Registry, ANZHTR will support broader advancements in thoracic organ transplantation and foster global collaborations aimed at improving patient care and transplant success rates worldwide.

Australia & New Zealand Lung Transplant Registry (ANZLUNG)

The Australia and New Zealand Lung Transplant Registry (ANZLUNG) is dedicated to monitoring the number and outcomes of patients diagnosed with advanced end-stage respiratory failure who have undergone lung transplantation. By maintaining a comprehensive database, ANZLUNG provides valuable insights into patient survival, post-transplant morbidity.

A key focus for ANZLUNG in 2025 will be the collection of historical lung transplant data dating back to the year 2000. This retrospective dataset will be built around a streamlined version of the minimum data set, enabling the identification of important trends in patient outcomes, complications, and mortality rates. By leveraging this historical data, transplant units will gain a clearer understanding of long-term survival patterns and factors influencing transplant success.

ANZLUNG is committed to strengthening data collection and reporting methodologies to ensure a more comprehensive understanding of lung transplant outcomes. Collaborations with transplant units across Australia and New Zealand will enhance the depth of data analysis, ultimately driving improvements in patient care and resource allocation. The Registry’s ongoing work will contribute to more refined clinical decision-making, policy development, and the evolution of best practices in lung transplantation.

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

The Australia and New Zealand Eye and Tissue Donation Registry (ANZETD) plays a critical role in reporting on eye and tissue donation and transplantation outcomes. These reports provide essential insights into sector activity, and outcomes. ANZETD works closely with key stakeholders, including the Australian Organ and Tissue Authority (OTA), Eye and Tissue Banks, both public and private. Additionally, ANZETD supports the professional societies governing this field, including the Eye Bank Association of Australia and New Zealand (EBAANZ) and the Biotherapeutics Association of Australasia (BAA).

ANZ ETD
AUSTRALIA & NEW ZEALAND
EYE & TISSUE DONATION REGISTRY

Throughout 2024, ANZETD has continued to enhance reporting accuracy, particularly within the eye donation and transplantation sector. A significant focus has been placed on identifying trends in donation rates, transplantation activity, and areas where demand exceeds supply. These insights are crucial in addressing service gaps and improving outcomes.

ANZETD strongly supports and actively contributes to national sector reviews, ensuring data-driven policy decisions and improved alignment with sector needs. ANZETD aims to provide a clearer picture of the total volume of human tissue product use. This will support more precise assessments of true demand versus supply within Australia and inform strategic planning for future resource allocation.

ANZETD’s work aligns with broader national initiatives, including The National Strategy for Organ Donation, Retrieval, and Transplantation, which seeks to improve access, equity, and outcomes across the organ and tissue donation sector and the Harmonisation of Human Tissue Acts, an ongoing effort to standardise legislation and regulatory frameworks across jurisdictions, ensuring consistency in tissue donation and transplantation practices.

Through these initiatives, ANZETD continues to strengthen the integrity and effectiveness of the eye and tissue donation reporting.

Australian Particle Therapy Clinical Quality Registry (ASPIRE)

The Australian Particle Therapy Clinical Quality Registry (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 four sites approved and awaiting site activation in early 2025 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 – site activation January 2025.

Six other hospitals or national services, including in the private sector, are at various stages within the approval process:

- Perth Children's Hospital, Western Australia
- Royal Brisbane and Women's Hospital, Queensland
- Sydney Children's Hospital, New South Wales
- Canberra Hospital, Australian Capital Territory
- ICON Cancer Centre, National network
- Princess Alexandra Hospital, Queensland.

ASPIRE increased its data collection this year at the Royal Adelaide Hospital to indications outside those listed in MSAC1638 but treated with PBT internationally. This was done to collect much needed evidence to expand the PBT eligible indications, as outlined in the Cancer Australia – '*Strategy for Proton Beam Therapy for Cancer Patients in Australia*' August 2023.

The ASPIRE National Steering Committee was successful in having their study protocol published in BMJ Open in 2024. "Australian Particle Therapy Clinical Quality Registry (ASPIRE) protocol (TROG 21.12): a multicentre prospective study on patients with rare tumours, treated with radiation therapy"
DOI: 10.1136/bmjopen-2023-083044

In summary, the past year has seen significant progress in the expansion of ASPIRE, positioning Australia at the forefront of photon/proton beam therapy research and treatment.

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.

BreastSurgANZ Quality Audit (BQR)

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 over the year include:

- Reached over 300,000 episodes of early and locally advanced breast cancer in the BQA database.
- Released 12 sets of data for approved research.
- Aotearoa New Zealand Protected Quality Assurance Activity (qualified privilege) application submitted and approved.
- Australian Quality Assurance Activity (qualified privilege) application drafted for submission in early 2025.
- Introduced quarterly participation and KPI reports.

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

Growing Participation

ANZELA-QI now includes 51 hospitals with 13,306 cases recorded. Despite complex ethics processes slowing site expansion, engagement across the sector continues to grow, strengthening the Registry's foundation for quality improvement and research.

Enhanced Reporting with Statistical Process Control (SPC) Charts

In 2024, ANZELA-QI, in collaboration with WA Health, significantly evolved its reporting by replacing traditional run charts with Statistical Process Control (SPC) charts, offering clearer insights into hospital performance and care quality trends.

Key milestones over the year include:

- **Improved reporting:** New monthly reports delivered consistently for six months, featuring 24 months of longitudinal data to meet the Australian Commission on Safety and Quality in Health Care's (ACSQHC) requirement for timely longitudinal reporting
- **Expanded Metrics:** Introduction of secondary KPIs, such as hospital journey times, for deeper understanding of care pathways
- **Data Quality Tracking:** Monthly data completeness metrics for each hospital and KPI, addressing ACSQHC's focus on data quality
- **State-Level Benchmarking:** Consolidated state reports for inter-hospital comparisons to drive improvement

Future Developments

Plans are underway to expand analyses and develop a real-time dashboard, with a draft anticipated by mid-2025, subject to funding and resources.

Advocacy for Mandatory Participation

Voluntary hospital participation, limits Clinical Quality Registries (CQRs) effectiveness. International models demonstrate that mandated involvement ensures comprehensive data and actionable insights. With the proposed introduction of Emergency Laparotomy Clinical Care Standards in 2025 and compliance reporting required by 2026, broader and mandatory engagement in CQRs will become essential. ANZELA-QI remains well-positioned to lead this evolution, driving clinical care improvements and supporting national standards through advanced reporting capabilities.

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 12 months ago, in November 2023. In its first year of operation, ARENA has recruited 4 national sporting organisations and has collected data from over 2,000 athlete cardiac screenings.

ARENA has published a protocol paper in the *Journal of the American Heart Association*, which was presented at the American College of Cardiology Care of the Athletic Heart conference and the Cardiac Society of Australia and New Zealand annual scientific meeting. An application for qualified privilege protection has also been submitted.

ARENA has already had impact, including:

- Endorsement from the Australasian College of Sport & Exercise Physicians (ACSEP) and Sports Medicine Australia (SMA);
- Implementation in the ACSEP Cardiac Screening Position Statement 2024:

  > *…all organisations with cardiac evaluation programs should be strongly encouraged to pool data to facilitate audit and further research. The ACSEP welcomes the recent creation of the Australasian Registry of Electrocardiograms in National Athletes (ARENA).*

- Specific inclusion in screening policies of several national sports
- Cited as the basis for implementation of new sports cardiology codes for the Orchard Sports Injury and Illness Classification System (OSIICS) version 15, one of the world's leading sports injury coding systems and one of two official coding systems used by the International Olympic Committee (IOC)

Researchers at ARENA are now conducting studies focussing on T wave inversion in female athletes and the epidemiology of premature ventricular contractions (PVCs). Work continues to support quality improvement initiatives in participating sporting organisations.

2024 ARENA Snapshot

Total cardiac screenings: 2,047

Athletes: 46% female / 54% male

Participating organisations: 4

Sports: 32

Publications: 1

Abstracts: 3

Presentations: 5

Coronary Angiogram Database of SA (CADOSA)

CADOSA
Coronary Angiogram Database of South Australia

The Coronary Angiogram Database of South Australia (CADOSA) is a clinical quality registry which captures consecutive public hospital patients undergoing coronary angiography and/or percutaneous coronary intervention (PCI) in South Australia. There are three components to the CADOSA Registry Program:

- Clinical Outcomes – detailed clinical data are obtained on each patient via patient interview and case note abstraction during hospitalisation. Clinical events over 12 months are obtained via data linkage
- Patient Health Outcomes – in selected patients, patient-reported health outcome measures (PROMs) concerning cardiac symptoms, impact on quality of life, and depression are obtained during hospitalisation and reassessed at 1 and 12 months via phone call
- Biobank – in selected patients, biological data is collected and stored for genetic, molecular and bioassay studies providing the capacity for precision medicine and discovery science

The CADOSA Registry infrastructure supports the monitoring and evaluation of health service delivery for cardiac catheterisation procedures, including procedural safety, performance and appropriateness. Research and innovation are also integral to the Registry Program. The inclusion of diagnostic angiography in addition to coronary intervention procedures allows for unique research opportunities concerning patients with non-obstructive coronary arteries (NOCA) including patients with myocardial infarction with non-obstructive coronary arteries (MINOCA), and angina with non-obstructive coronary arteries (ANOCA).

The many CADOSA partnerships, include the National Cardiac Registry (NCR), an Australian Government Health Department entity which has established a national database of PCI procedures. In 2024, CADOSA contributed to the NCR Annual report which includes South Australian public hospital PCI procedures for 2023: https://nationalcardiacregistry.org.au/2024-annual-status-report/

The Personalising Acute Myocardial Infarction Care to improve Outcomes (PAMICO) Project

This year, CADOSA Investigators Prof John Beltrame and A/Prof Rosanna Tavella, led the implementation of the PAMICO Project in CALHN. PAMICO is an NHMRC Partnership grant which aims to improve health outcomes and health care delivery for acute myocardial infarction (heart attack) patients undergoing angiography. PAMICO has involved the 1) regular review and feedback of the clinical care standards using CADOSA data, which has demonstrated optimal adherence of the standards in heart attack patients, and 2) deployment of ePRISM, a digital health tool which allows real-time risk model calculation based on simple clinical data. This has provided personalised risk estimates for each heart attack patient for important outcomes including angiography complications and length of stay, the first of its kind in Australia. The next phase of PAMICO will evaluate the impact of the personalised risk predictions on in-hospital outcomes.

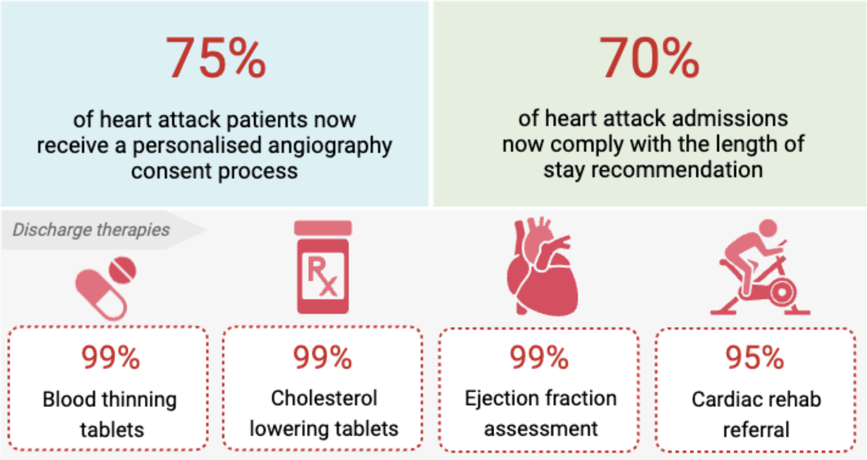


Figure 1. PAMICO Impact in 2024, including the implementation of personalised risk information for angiography consent and length of stay prediction for acute myocardial infarction (MI) patients, and a summary of CADOSA data showing optimal compliance with the clinical care standards for acute MI patients undergoing angiography in Central Adelaide Local Health Network (CALHN).

2024 CADOSA Student Research Training

CADOSA has supported research projects for over 11 PhD candidates, and currently we have five PhD candidates utilising the CADOSA infrastructure for their studies. In 2024, CADOSA research focusing on characterising the clinical outcomes and endotypes of ANOCA patients was presented at the European Society of Cardiology by the following PhD students:

Sarena La
Does ischaemia testing predict worse adverse outcomes in ANOCA patients?
https://esc365.escardio.org/ESC-Congress/sessions/8135

Olivia Girolamo
Coronary slow flow as measured by corrected TIMI frame counts is associated with impaired microvascular resistance
https://test-digital-congress.escardio.org/ESC-Congress/speakers/1122082

Additionally, results from our basic laboratory studies aimed at developing our mechanistic understanding of ANOCA disorders was presented at the Cardiac Society of Australia and New Zealand Conference by our PhD Candidate:

Alex Minopoulos
Effect of Vericiguat Pre-treatment on Phenylephrine Constrictor Responses in Isolated Human Internal Mammary Artery Segments With/without Intact Endothelium
https://www.heartlungcirc.org/article/S1443-9506(24)01417-3/fulltext

Additionally, **Dr Adeel Khoja** published his final PhD study using CADOSA data:
Khoja A, Andraweera PH, Tavella R, Gill TK, Dekker GA, Roberts CT, Edwards S, Arstall MA. *Influence of Socioeconomic Status on the Association Between Pregnancy Complications and Premature Coronary Artery Disease: Linking Three Cohorts. Womens Health Rep* (New Rochelle). 2024 Feb 16;5(1):120-131. doi: 10.1089/whr.2023.0092. PMID: 38404672; PMCID: PMC10890942.

Lastly, in 2024, we supervised six undergraduate students using CADOSA data for their research placements.

2024 Post-Doctoral Research Studies

In 2024, two post-doctoral researchers led independent research projects utilising CADOSA data and the Registry infrastructure. These studies were supported by grants awarded by The Hospital Research Foundation Group:

Dr Clementine Labrosciano
Readmission Risk Prediction Following Acute Myocardial Infarction
This study is utilising CADOSA data to develop a readmission risk prediction model to identify myocardial infarction patients who at high risk of 30-day all-cause readmission
https://australianheartresearch.org.au/news-stories/latest-news/reducing-heart-attack-readmissions/

Dr Tharshy Pasupathy
The Anti-Anginal Benefits of Zinc in ANOCA Patients (ZIANOCA Trial)
Building on findings from the CADOSA Biobank led by Dr Peter Zalewski, which showed the importance of zinc homeostasis for the vasculature, including potentiating vasodilator (relaxation) responses, this research is utilising the CADOSA Registry infrastructure to run a randomised controlled trial to assess the impact of Zinc therapy on angina symptoms in ANOCA patients
https://australianheartresearch.org.au/news-stories/latest-news/fighting-to-alleviate-chest-pain-through-zinc/

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

SA Birth Defects Register (SABDR)

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.

In 2024, the SABDR published “Congenital Anomalies in South Australia, 2019”, which provides new notification data on congenital anomalies in South Australia for the 2017-2019 calendar years, and updates data from earlier years.

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.

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)

The South Australian Cerebral Palsy Register is a population-based collection of information on children with cerebral palsy born in South Australia. In 2024, the latest annual SACPR report was published, presenting information for children with cerebral palsy born in the years 1993-2018. 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 1.71 per 1,000 live births (2016-2018). This is in line with data presented by the Australian Cerebral Palsy Register, which reported an overall rate for Australia of 1.5 per 1,000 live births for the 2015-2016 birth years, 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 is expected to be published in early 2025 and will show the current prevalence trends for cerebral palsy across Australia.

During 2024, a focus for the team has been the development 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 working with clinicians to offer 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.

SCAN ME

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

The Australia and New Zealand Vasculitis Quality and Disease Registry (ANZVASC-QDR) is a new registry, founded by members of the ANZ Vasculitis Society (ANZVASC), that aims to improve the quality of care of people with vasculitis. Monash University is the host and data custodian. The ANZVASC focusses initially on people with ANCA-associated vasculitis (AAV), with the capacity to include other forms of vasculitis, particularly large vessel vasculitides such as giant cell arteritis.

During 2024, we enrolled most available patients at the Monash Health site. With the migration of participants' data from the older Monash registry, we now have up to 8 years follow up. Three new sites commenced on 9 Dec 2024. Six registry sites have completed (or are signing) governance agreements. An EOI for new sites will take place in early 2025.

Members of the registry have undertaken a priority setting exercise to determine the key reporting outcomes for the ANZVASC-QDR, determined both by people with AAV and by vasculitis clinicians. Outcomes include patient reported outcomes and clinically defined outcomes. Round 1 of the Dephi survey has so far attracted over 200 participants from Australia and New Zealand, as well as the UK and Ireland.

In 2025, the ANZVASC-QDR will 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. We anticipate the first publications and yearly report from the Registry in 2025.

International Vitreoretinal B-cell Lymphoma Registry (IVRLR)

Vitreoretinal lymphoma is an aggressive 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* is at a relatively early stage of development. After publishing our first report at the end of 2023, we have focused our efforts in 2024 on building capacity, working to recruit and train contributing ophthalmologists who diagnose and treat vitreoretinal lymphoma globally. Speaking at meetings about the project and publication of the first report have been successful means for 'spreading the word'. At the end of 2024, there are 62 ophthalmologists and other expert clinicians (from 15 countries) actively contributing to this effort, in addition to the local research team.

Meetings have been both international and local. On invitation, we have spoken at the premier international retina meeting, Euretina Congress (Barcelona, Spain), as well as the popular Eastern European meeting, Filatov Memorial Lecture Series (Odesa, Ukraine). Prof. Justine Smith discussed the project during her plenary 'Council Lecture' at the Annual Scientific Congress of the *Royal Australian and New Zealand College of Ophthalmologists*, using it as an example of productive international collaboration. The project was also reported at the local Flinders Health and Medical Research Institute Cancer Symposium. In addition, we wrote an invited editorial for *Clinical and Experimental Ophthalmology* (ranked 6th out of 95 peer-reviewed ophthalmology journals) on the treatment of vitreoretinal lymphoma.

In 2025, we plan to time-censor the project, enabling us to prepare reports on the clinical features that characterise a presentation of vitreoretinal lymphoma, and the prediction of outcomes in this cancer.

Australian and New Zealand Audit of Surgical Mortality (ANZASM)

Royal Australasian College of Surgeons
Australian and New Zealand Audits of Surgical Mortality

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 RACS in all Australian states and territories except for NSW, where a similar program is run by the Clinical Excellence Commission with support from RACS.

As of 31 December 2024, ANZASM had facilitated the review of 60,947 instances of patient in-hospital mortality where surgical care was involved (since its inception), with a further 8,696 cases excluded from the full review process due to being terminal care admissions. The median age of these patients was 77 years (interquartile range 65–85), they were 56.4% male and constituted emergency presentations with an acute life-threatening condition in 84.9% of cases. In terms of risk profile, 84.5% of patients presented with an ASA score (American Society of Anesthesiologists physical classification system) of 3 or higher, with 87.3% of patients having at least one comorbidity. Following independent review, it was considered that in 19.3% of cases clinical management could have been improved, with operative management issues and operative decision being the two main areas for improvement.

This process has helped inform the recommendations made in reports and the educational events ANZASM has held over the past year, including webinars addressing the complexities of patient transfer, challenges in the management of patients presenting with hip fractures, and surgical considerations for vulnerable patients.

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

SA-PCCOC
South Australian
Prostate Cancer
Clinical Outcomes Collaborative

SA-PCCOC had an eventful year in 2024 particularly navigating a change in database system to align more closely with the Prostate Cancer Outcomes Registry of Australia and New Zealand (PCOR-ANZ). Despite challenges, the team has maintained excellent recruitment rates with the registry now holding data on over 22,500 men diagnosed with prostate cancer. The team continues to optimise data access and flow in the new platform.

SA-PCCOC contributed to a consumer forum on prostate cancer held at Flinders Medical Centre in 2024; and co-hosted the 2024 SA Prostate Cancer Research Symposium. This event attracted researchers and clinicians from across the state and was made possible by generous industry sponsorship.

SA-PCCOC continues to grow its research output with eight papers in 2024 and provides mentorship for eight 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. The registry acknowledges generous support from the Movember Foundation, The Hospital Research Foundation, and the Urological Society of Australia and New Zealand.

Australian and New Zealand Registry of Advanced Glaucoma (ANZRAG)

AUSTRALIAN & NEW ZEALAND
REGISTRY OF ADVANCED GLAUCOMA

The Australian and New Zealand Registry aims to identify novel genetic risk factors for glaucoma blindness and has recruited 9571 individuals over the past 17 years. The recruitment is ongoing with an additional 368 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 (24%), and then early Glaucoma suspects (20%). There are 235 specialists from across Australia and New Zealand who have referred participants to ANZRAG. Participants from every state and territory, including New Zealand, Canada and the UK have been recruited and provided a DNA sample in 2024.

In 2024, ANZRAG now includes additional sites at the Queen Elizabeth Hospital (QEH), Royal Adelaide Hospital (RAH), Women's and Children's Hospital (WCH) and Royal Victorian Ear & Eye Hospital (RVEEH).

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.

There have been 5252 individuals screened for the MYOC gene (the most common gene associated with adult-onset glaucoma) and 176 individuals with Primary Congenital Glaucoma have been screened for CYP1B1. Familial testing for these genes and others identified is offered on an ongoing basis to those family members interested. We have performed exome sequencing on 1901 individuals with glaucoma and family members recruited, as well as genome sequencing on 480 individuals with early onset glaucoma (as part of an NIH grant). We have now performed SNP arrays on 8509 individuals to calculate their glaucoma polygenic risk score (PRS).

Exome data analysis led to the discovery of a novel candidate gene for primary congenital glaucoma in collaboration with Prof Wiggs.

Selected advanced and non-advanced glaucoma cases from the ANZRAG (N=3975) have now formed the cohort for the TARRGET study (SACHREC 98-15) which informs first-degree relatives of their risk of developing glaucoma.

Presentations:

Dr Antonia Kolovos. The Royal Australian and New Zealand College of Ophthalmologists 55th Annual Scientific Congress 01 NOV ‐ 04 NOV 2024 Adelaide, Australia. A novel application of a primary open-angle glaucoma polygenic risk score determines pigmentary glaucoma.

Dr Antonia Kolovos. The Royal Australian and New Zealand College of Ophthalmologists 55th Annual Scientific Congress 01 NOV ‐ 04 NOV 2024 Adelaide, Australia. A polygenic risk score (PRS) for POAG identifies patients at risk of glaucoma progression.

Prof Jamie Craig. The Royal Australian and New Zealand College of Ophthalmologists 55th Annual Scientific Congress 01 NOV ‐ 04 NOV 2024 Adelaide, Australia. Genome wide association study for pRNFL thickness in PROGRESSA and ANZRAG cohorts identifies multiple genome wide significant loci.

Australian Corneal Graft Registry (ACGR)

The Australian Corneal Graft Registry had another excellent year in 2024. The database now contains over 47,500 registered corneal transplants in over 32,500 individual graft recipients, and follow-up has been received for almost 40,000 grafts. More than 12,500 (27%) grafts continue to be followed, with an annual request for follow-up sent to surgeons in September. Contributing surgeons provided follow-up information for 6,400 grafts during 2024. The longitudinal nature of the ACGR is one of its greatest strengths and 239 grafts have now been followed for more than 30 years, with 43 grafts stretching to over 35 years.

In July 2024, the main offices of the ACGR relocated to the newly completed Health and Medical Research Building, a state-of-the-art research facility at Flinders University. An on-site presence is also maintained at SAHMRI to facilitate collaboration with other registries. In September, we were pleased to have been accepted for inclusion on the Australian Commission on Safety and Quality in Health Care Register of Clinical Quality Registries.

The ACGR gave a presentation at the SAHMRI Registry Centre Symposium held in March 2024, in the health economics and clinical practice impact section of the programme. In June, we were invited to give a presentation on our operations and the importance of our data at The Eye Health Centre CPD Conference for optometrists and orthoptists in Brisbane. Representatives from the ACGR also attended the Fundamentals of IMPACT Workshop held at SAHMRI in August. We have also been delighted to work with SAHMRI Registry Centre staff, and other member registries, on the Consumer Friendly Information (COFI) project this year.

The latest major report for the Registry was released in 2022 (available online at https://doi.org/10.25957/9vyp-0j93) and continues to be downloaded internationally. Preparations for the next major report commenced in July, with data cleaning and univariate analyses close to completion at the end of 2024, and on track for an anticipated June 2025 report release. Two annual reports were produced in 2024. An interim report to contributors was presented at the annual Australia and New Zealand Corneal Society Meeting held in Melbourne in March. A further written report, summarising the data contained in the ACGR database as at 30th June 2024, 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.

Kidney Health Registry

The Kidney Health Registry based at Flinders Medical Centre was established jointly by the Department of Nephrology and Department of Urology at the Southern Adelaide Local Health Network (SALHN) in 2020. It is a database of information about patients above the age of 18 who have had a nephrectomy (complete or partial kidney removal) due to kidney cancer, infection or other reasons. It also includes information about patients who are treated non-surgically for kidney cancers and patients on surveillance for kidney cancer/mass/complex cysts.

The registry was created to monitor the long-term clinical outcomes of nephrectomy. It also monitors the outcomes of other non-surgical treatments for kidney cancers. It collects information about these patients such as follow up assessments, treatments, and health-related quality of life (HRQOL).

Currently, this registry has information about approximately 800 patients treated in Flinders Medical Centre, Noarlunga Hospital or Repatriation General Hospital since 2005.

In 2024, North Adelaide Local Health Network (NALHN) has been added as an additional site of the Registry which will recruit patients from the Lyell McEwin Hospital.

Research projects currently using the data from the Registry include - development of a score to predict risk of developing chronic kidney disease post-nephrectomy and assessment of outcomes of different methods of managing small renal masses/cancer and renal cysts. One of the projects which involved assessment of quality of life of people who have undergone Nephrectomy has been completed successfully in 2024, the findings of which will be prepared for publication this year.

Finally, the Kidney Health Registry aims to aid 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 goal is to expand this registry to other health networks across South Australia and eventually become a national nephrectomy registry.

Lily Registry

An Australian first, a clinical registry to understand the mysterious medical instability of eating disorders.

The prevalence of eating disorders is increasing in Australia, with 1-4% of the population being affected. The acute hospital is complex, prolonged and challenging for patients and the care team. There is a lack of information and understanding about this patient group and the care they receive. This correlates with a lack of evidence-based protocols describing best practice care and studies to deepen understanding and improve care.

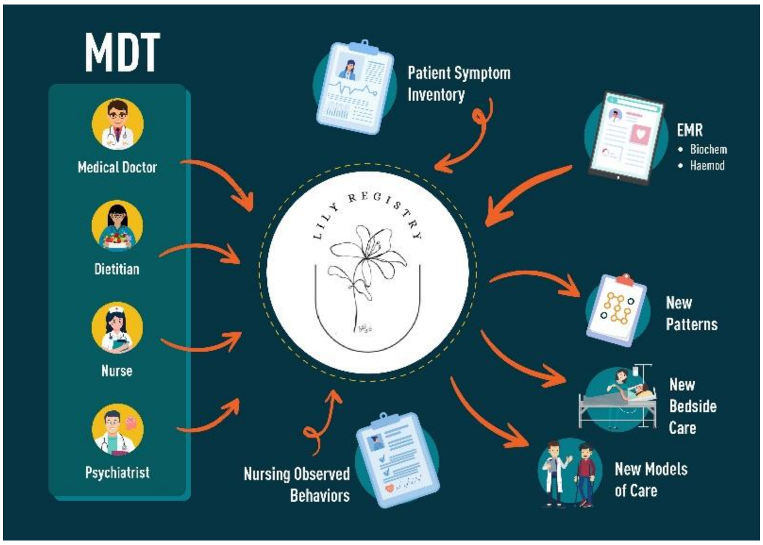
The Lily Registry has recently relocated to SAHMRI. Currently there is no other registry in Australia that systematically documents eating disorder treatment and outcomes for those patients who require hospitalisation. This statewide CQR was developed to support best-practice multidisciplinary care and continuous quality improvement for this patient cohort.

The first patient was enrolled mid 2023 at the Royal Adelaide Hospital with recruitment at the Women's & Children's Hospital commencing in 2024. Governance approval is currently being sought at a 3rd LHN in South Australia, alongside conversations with interstate partners in VIC & NSW for national expansion.

Features of the Registry:

- Hosted on the Data Dissect platform – 'Software as a Service'
- eConsent solution for patients to provide their informed 'opt-out' consent to participate
- Patient engagement with the secure patient portal for online collection of responses to the Symptom Inventory ED–15 questionnaire
- A collaborative approach of an MDT format providing a single view of the patient
- Secure access to protect the confidentiality of patient data
- Centralised Registry Service – a consolidated insights repository of de-identified data from multiple sites for real-time research.

The Lily registry acknowledges the generous support from the South Australian Association of Internal Medicine, SAHMRI and the Registry Centre.



PRODUCT REGISTRIES

Transcatheter Aortic Valve Implantation **(TAVI)**
Dental Implant Registry **(DIR)**

Transcatheter Aortic Value Implantation (TAVI) Registry

The Transcatheter Aortic Valve Implantation Registry (TAVI) is a clinical quality registry supported by the Australasian Cardiac Outcomes Registry (ACOR) Ltd to monitor procedural and clinical outcomes of patients undergoing aortic valve replacement via a transcatheter approach.

The Registry team have been working towards the expansion of the registry to collect procedural data for all four cardiac valves (aortic, mitral, pulmonary and tricuspid). This is an exciting and significant expansion of the registry and will assist achieving ACOR's goal of improving the outcomes following cardiac procedures and contributing to the continuous improvement of clinical practice and patient outcomes in cardiovascular disease. The collection and reporting of this data will help close the gap from research-to-research findings to the guidelines for the practical application of procedural techniques that improve the quality of health care in Australia and New Zealand.

Highlights of 2024

- An additional 2 sites commenced data collection, bringing the total to 54 sites nationally
- The registry has now collected over 24,000 TAVI cases since its inception
- Continued to improve the management of data, reporting and ad-hoc data request provision
- Participated in an industry TAVI Coordinator Education Workshop
- Participated in the preparation of TAVI consumer information for the TAVI Registry 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 (tender Health/E23-209685)

The TAVI Registry is:

- Listed on the Australian Commission on Safety and Quality in Health Care, Register of Registries
- A member of the SAHMRI Registry Centre Advisory Committee, and
- ACOR TAVI Steering Committee and Working Group.

Dental Implant Registry (DIR)

The **Dental Implant Registry (DIR)** is a comprehensive, web-based registry dedicated to enhancing the safety, effectiveness, and long-term outcomes of dental implant components and procedures in Australia and New Zealand. According to the Therapeutic Goods Administration (TGA), dental implants are classified as a Type IIb Medical Device, indicating a moderate to high risk level.

The primary objective of the DIR is to collect and analyse data to improve patient outcomes and refine clinical practice. The registry facilitates research into risk factors, procedural techniques, and patient demographics while fostering collaboration among dental practitioners, manufacturers, and regulatory bodies. This collective effort aims to minimise complications such as infections, fractures, and implant loosening.

The DIR serves a dual purpose as both a registry and a register, providing a secure storage platform for implant component details. By facilitating the secure sharing of information, it enhances communication between treating clinicians, laboratory staff, and patients, ultimately contributing to improved patient outcomes.

Key Highlights from 2024:

- **Full ethics approval:** In January 2024, the DIR received full ethics approval for its project, *"Registry of Australian and New Zealand Dental Implant Devices and Procedures."*
- **Team expansion & system upgrades:** The addition of an IT Program Manager enabled significant system enhancements, improving app functionality, user experience, and the quality and quantity of collected data.
- **Industry engagement:** DIR team members actively participated in key industry events, raising awareness and fostering connections among dental professionals and health stakeholders.

DIR representatives attended key conferences to promote the benefits of the registry:

- **ANZAOMS 2024 Annual Scientific Meeting** – Australian and New Zealand Association of Oral & Maxillofacial Surgeons (Cairns)
- **AOS, ASP & APS Combined Conference** – Australian Osseointegration Society, Australian Periodontal Society, and Australian Prosthodontic Society (Gold Coast)
- **Arab Health, Global Healthcare Medical Expo 2025-** Dubai

Looking Ahead:

In 2025, the DIR is committed to further **expand its reach and impact** through the following key initiatives:

- **Increasing consumer awareness** through targeted engagement strategies
- **Strengthening relationships** with regulatory bodies and health institutions to improve compliance and data integration
- **Enhancing governance structures** by expanding the advisory board, incorporating diverse expertise, and refining policies to ensure transparency and accountability
- **Developing strategic partnerships** with industry leaders and research institutions to support innovation and evidence-based advancements in dental implant procedures
- **Continuing system upgrades** to optimise data collection, user experience, and reporting capabilities
- **Publishing its first collaborative journal article, *in the Australian Dental Journal*,** marking a significant milestone in advancing research and collaboration within the field

By strengthening governance, fostering collaboration, and expanding awareness, the DIR aims to further solidify its role as a leading resource for dental implant safety and effectiveness in Australia and New Zealand.

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