



REGISTRY CENTRE
A CENTRE OF EXCELLENCE FOR
REGISTRIES AND REGISTRY SCIENCE

SAHMRI Registry Centre

Annual Report 2023



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

The co-location of registries at SAHMRI provides a unique point of difference for the institute, which strives to ensure they are optimally utilised by policy makers, health services and researchers across South Australia and nationally.

As a centre of excellence for registries and registry science, the SAHMRI Registry Centre brings together registries based throughout South Australia and nationally. The Centre fosters collaborations that are of enormous value to health systems delivering impact across health policy, clinical practice, the health economy and consumer and patient outcomes while simultaneously creating innovative new research pathways.

The SAHMRI Registry Centre was established in 2018 to strengthen the voices of member registries nationally, their individual and coordinated capacity, reach and influence in this and other important areas.

Australia's registry science sector is still developing but is making impressive progress, with the SAHMRI Registry Centre playing an important role. Registries across Australia are making important findings that can very quickly facilitate improved quality of care, better decision making and better outcomes in the real world.

There is much to expect from our Centre over the next few years as the funding from the Australian Government Department of Health and Aged Care, under the National Clinical Quality Registry Program, supports several projects with a central focus on promoting best practice and communicating health outcomes to the public.

The Centre's educational activities continue to be well received and are growing and contributing to the development of the workforce.

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. In the current climate of rising health costs, the efficiency and cost effectiveness of these valuable resources is critical. The Centre remains committed to creating an environment where clinical quality registries share resources and knowledge to provide value to funders and the community.

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

Caroline Miller

Contents

LETTER FROM THE CHIEF OPERATING OFFICER & DIRECTOR, HEALTH POLICY CENTRE	2
LETTER FROM THE SAHMRI REGISTRY CENTRE STRATEGIC DIRECTOR	4
INTRODUCTION	5
PURPOSE	5
AIMS	5
GOVERNANCE	5
REGISTRY CENTRE ACTIVITIES	6
Australian Registry Annual Scientific Meeting	7
CQR Communication and Collaboration Hub	7
2023 Registry Centre Workshop	6
Statistical Education Forums	6
A Community of Practice (CoP) on Consumer Engagement for the SAHMRI Registry Centre	6
2024 Registry Centre Annual Scientific Symposium	6
SUMMARY	7
REGISTRY HIGHLIGHTS	8
Registry Of Senior Australians (ROSA)	10
Australia & New Zealand Dialysis & Transplant Registry (ANZDATA)	11
Australia & New Zealand Eye Tissue Donation Registry	13
Australia & New Zealand Organ Donor Registry	14
Australia & New Zealand Living Kidney Registry	15
Australia & New Zealand Heart Transplant Registry (ANZHTR)	16
Australia & New Zealand Lung Transplant Registry (ANZLUNG)	16
Australian Particle Therapy Clinical Quality Registry (ASPIRE)	17
BreastSurgANZ Quality Audit (BQA)	19
ANZ Emergency Laparotomy Audit – Quality Improvement (ANZELA-QI)	19
Australasian Registry of ECGs of National Athletes (ARENA)	20
SA Birth Defects Register (SABDR)	22
SA Cerebral Palsy Register (SACPR)	22
The Australia and New Zealand Vasculitis Quality and Disease Registry (ANZVASC-QDR)	23
International Vitreoretinal B-cell Lymphoma Registry	23
Australian and New Zealand Audit of Surgical Mortality (ANZASM)	24
South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC)	25
Australian and New Zealand Registry of Advanced Glaucoma (ANZRAG)	26
Australian Corneal Graft Registry (ACGR)	27
Kidney Health Registry	28
Transcatheter Aortic Valve Implantation (TAVI-R) Registry	30
Dental Implant Registry (DIR)	31

Letter from the SAHMRI Registry Centre

Strategic Director

I am pleased to present the second SAHMRI Registry Centre Annual Report. This year saw us consolidate the Centre, making it sustainable while delivering on its purpose and goals.

The Registry Centre continues to support a shared learning environment by delivering high quality education opportunities that build capacity within the clinical quality registry sector. This work, along with our strengthening relationship with the Department of Health and Aged Care and growing profile in the sector, has been instrumental in our funding success this year.

In 2023 the Centre welcomed three new registries to the collaboration:

- The Australian Registry of ECGs of National Athletes (ARENA) - Sydney University
- The Australia and New Zealand Vasculitis Quality and Disease Registry (ANZVASC-QDR) – Monash University
- The Kidney Health Registry - Flinders University

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

This year the SAHMRI Registry Centre secured \$700,000 funding to ensure Australians are maximising the health benefits from discoveries made by registry science. That funding from the Australian Government Department of Health and Aged Care, under the National Clinical Quality Registry Program, will support several projects with a central focus on promoting best practice and communicating health outcomes to the public.

The Centre is moving to a model of project delivery through centralised project management. This uses our expertise to expand and enhance best practices in registry science while driving innovation and development across the 22 member registries and the broader CQR sector where appropriate.

The funding from the Department of Health and Aged Care is for the provision of activities that support continued implementation of the National Clinical Quality Registry and Virtual Registry Strategy.

1. Registry Centre of Excellence – The Centre of Excellence for Registries and Registry Science
Activities include an initial 18-month work program to cover the following activities:
 - a. Increasing CQR sector capability in public reporting
 - b. Pilot CQR advisory service
 - c. Increasing CQR value and impact – case studies and analysis
 - d. Increase registry capability in data linkage
2. Consumer Friendly Information – the CoFI project is designed to create and disseminate easily understandable and reliable outcome information direct from registries to empower consumers and their families to make informed decisions about their health. It will be delivered over an 18-month period commencing January 2024. This project is a collaboration across ROSA, the Australian Corneal Graft Registry (ACGR) and the Transcatheter Aortic Valve Implantation (TAVI) Registry.

This expansion of funding and projects means new team members joined the Registry Centre in February to enable the delivery of these important projects. We are looking forward to a busy 2024!

Cindy Turner

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) has funded the SAHMRI Registry Centre since May 2022.

The Centre is now moving to a model of project delivery through centralised project management using our expertise to expand and enhance best practices in registry science and driving innovation and development across the 22 Centre member registries and the broader CQR Sector when appropriate.

The SAHMRI Registry Centre Executive Group

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

- 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 goals.

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/ Emma Heath / Michelle Lorimer	TAVI
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
Professor David Roder	Cancer Population Registries
A/Prof Rosanna Tavella	University of Adelaide (guest)
Helen Thomas	Wellbeing SA

**Representatives may change throughout the year*

Registry Centre Activities

2024 Registry Centre Annual Scientific Symposium

The Registry Centre is busy planning the Annual Scientific Symposium for 2024 to be held on March 27, 2024, with a theme of 'The Value and Impact of Clinical Quality Registries – *catalysts for change in policy and practice*'.

The symposium will coincide with the release of this report and is shaping up to be an exciting event with international speaker Dr Freddie Bray, Head of Cancer Surveillance Branch, The International Agency for Research on Cancer (IARC), World Health Organisation as the keynote speaker. Other invited speakers include:

- Professor Danny Liew
- Professor Caroline Miller
- Professor Ian Harris
- Professor Gillian Caughey
- Dr Paul Secombe

Included in the program will be a series of real-life case studies demonstrating the value and impact of member registries across the areas of clinical practice, policy, research, consumers and health economics.

2023 Registry Centre Workshop

The Registry Centre was delighted to have Professor Tim Beukelman as our guest speaker in July. Timothy Beukelman, MD, MSCE is a paediatric rheumatologist and clinical epidemiologist. He was a founding member and is the current Scientific Director of the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Registry. This prospective observational registry has enrolled more than 12,000 children with arthritis, lupus, and dermatomyositis at 70 clinical sites in the United States and Canada. The Registry has collaborated with multiple pharmaceutical companies to conduct post-market (phase IV) safety studies and report on real-world medication use and effectiveness.

Professor Beukelman's session 'Using a prospective observational registry to produce real world evidence suitable for pharmaceutical companies and regulatory agencies—The CARRA experience' was well received by the sector and we look forward to having further guest speakers of this calibre throughout 2024.

Statistical Education Forums

Demand for the SAHMRI Statistics Education Forums continues to grow, in 2023 eight education forum sessions were held 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 have now been opened more broadly to the statistics and analytics workforce.

A Community of Practice (CoP) on Consumer Engagement for the SAHMRI Registry Centre

The Registry Centre continues to connect and participate in the Consumer Engagement CoP and is working closely with Health Translation SA (HTSA) to develop the program for 2024. Involvement in the CoP will strengthen our work on the newly funded Consumer Friendly Information (CoFI) project. All member registries have the opportunity to participate in the CoP workshops of which five were held across 2023 and to have their consumer representatives included on the HTSA Community Interest Register.

Australian Registry Annual Scientific Meeting 2023

As part of the Organising Committee, the Centre contributed to a successful Australian Registry Annual Scientific Meeting, held on the 19th - 20th October 2023 at the Alfred Health Innovation and Education Hub, Melbourne, hosted by Monash University. The two-day event presented a broad range of high-quality speakers and presentations and is becoming a premier registry event annually in Australia.

CQR Communication and Collaboration Hub

The Hub is partnership between Monash University, SAHMRI and the Australian Clinical Trials Alliance, supported by the Commonwealth Department of Health and Aged Care's CQR program. The Hub plans to deliver programs across four key areas:

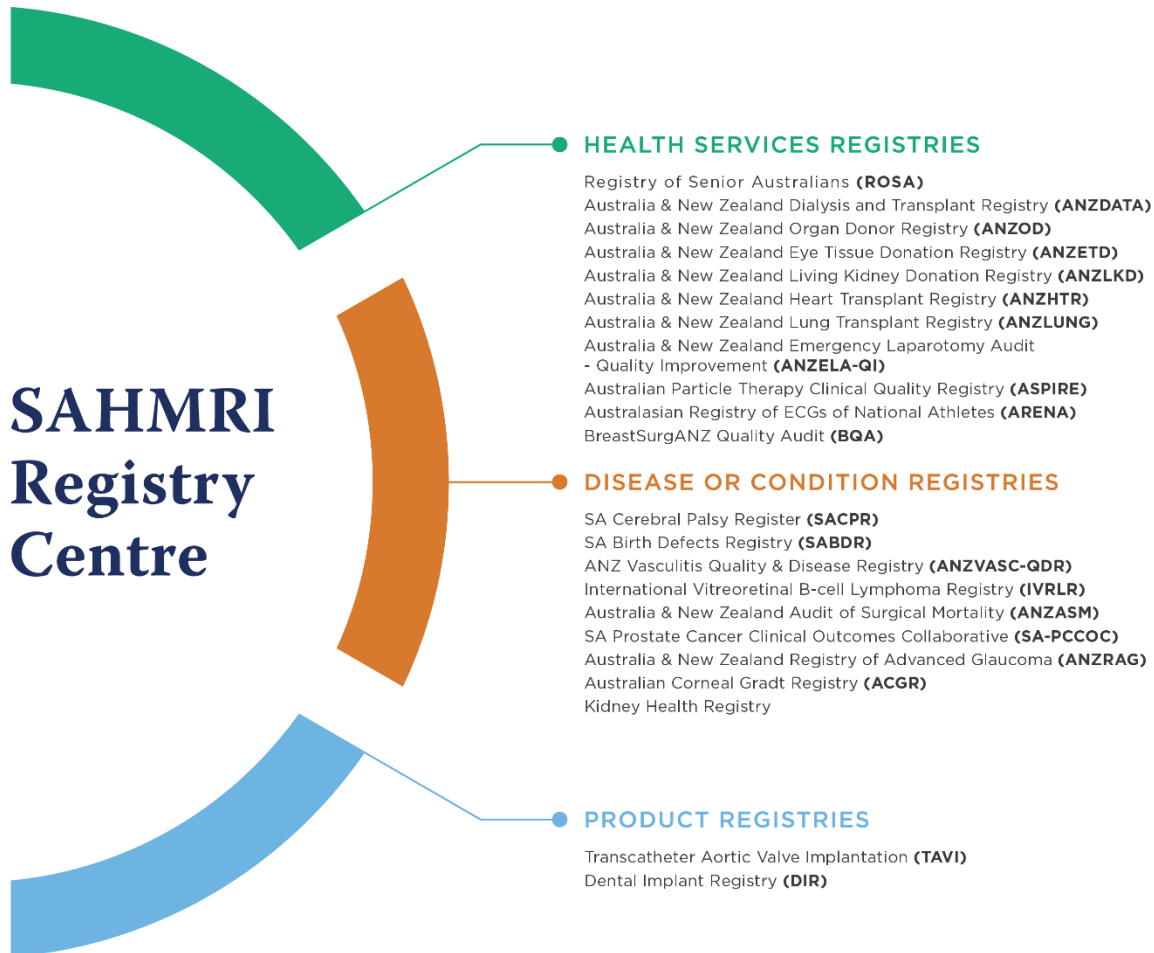
- *Professional Development Program*: this program includes the Australian Registry ASM, the SAHMRI Registry Centre Symposium and two Registry Special Interest Group (SIG) webinars
- *CQR Communication and Collaboration* – it has been exciting to be part of the first two editions of the Benchmark quarterly newsletter, providing an avenue for communication and information within the sector.
- *Development of resources for the CQR sector*: a key resource being investigated is the development of a Good CQR Practice Guide and Training Module. There will be further updates as this project progresses throughout the year.
- *Promotion of Registry Science*: the Registry Centre will continue to contribute to the promotion of registry science through all opportunities presented to us and the Hub will provide further avenues to continue this work.

Summary

This report presents the activities of the Registry Centre over the last 12 months and importantly announces the beginning of a new era for the Registry Centre as we embark on important projects. In particular, the CQR Advisory Service will be an important development and transform the existing ad hoc support the Centre provides across the sector into a more formalised service. The CQR Advisory Service can be contacted on registrycentre@sahmri.com or by speaking directly to the Strategic Director, Cindy Turner (08) 8128 4281.

The Consumer Friendly Information (CoFI) is an exciting project, and we are looking forward to working closely with consumers to translate registry outcome data into valuable consumer friendly resources.

Registry Highlights



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**)
- 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**)

Registry Of Senior Australians (ROSA)

The Registry of Senior Australians (ROSA) is an Australian Clinical Quality Registry and data platform designed to monitor and evaluate the health, service use, medication use, mortality, and other important outcomes of people receiving aged care services in Australia. In 2023, the ROSA team published 15 academic studies and contributed to the delivery of four reports. One of the reports was delivered to the Australian Government Medical Services Advisory Committee to support the evaluation of a novel Australian Government Medical Benefits Schedule subsidy for facilitating access to mobile X-ray services in aged care facilities.

The team also had several grant successes including Prof Gillian Caughey (ROSA Associate Director) being awarded a NHMRC Investigator Grant to continue her research program which will build the evidence to inform and evaluate the impacts of quality of care reforms to Australia's aged care system.

Other ROSA early-career researcher successes included Dr Tesfahun Eshetie who was awarded a Health Translation SA MRFF Catalyst grant for his project which will leverage ROSA data to examine the characteristics of carers and their caregiving roles, and how they influence unplanned hospitalisations and quality and safety of care. Finally, Dr Stephanie Harrison received funding from the Stroke Foundation to examine the long-term care older people in Australia receive after stroke and determine factors which might impact the types of long-term care they receive.

ROSA was selected as a finalist in the Research Australia 2023 Health and Medical Research Awards 'Data Innovation Category', which recognised the team's contributions of creating Australia's only national multisectoral integrated data platform designed for the population-level evaluation of quality of care, models of care and national health priority areas that affect older people. The ROSA governance committee members, partners and our team also received a Highly Commended outcome in the 'Research' category for the 2023 Future of Ageing awards administered by Inside Ageing.

In addition, the ROSA Outcome Monitoring System (OMS) was also selected as one of SAHMRI's '10 Grate Achievements' as part of SAHMRI's 10-year celebrations. This recognition of our pragmatic quality and safety monitoring system designed to support benchmarking and inform quality improvement initiatives was an incredible accomplishment by the ROSA OMS Advisory Committee and our team.

The ROSA OMS reports were released for Residential Aged Care services in September 2022 and the Home Care reports were released June 2023. These direct-to-provider reports were made available to almost 150 South Australian residential aged care or home care services between 2022/23 (<https://rosaresearch.org/rosa-oms>).

In October 2023, we received a data linkage update of the ROSA Prospective (South Australia only) cohort, which now includes information for 53,300 individuals assessed for and/or receiving aged care services in South Australia between 2018-2022. These data will inform the next release of the direct-to-provider ROSA OMS reports scheduled to become available in early 2024.





Australia & New Zealand Dialysis & Transplant Registry

(ANZDATA)

In 2023, the clinical quality registry of ANZDATA (Registry) and the research it generates continued to focus on improving the quality of care and outcomes for people with end-stage kidney disease in Australia and New Zealand.

Guided by and serving the kidney community, our primary activity of quality and safety reporting encouraged contributors (kidney dialysis and transplant units) to reflect on their service provision, review patient-centric health targets and monitor outlying indicators to achieve better health outcomes for kidney patients everywhere.

Supported by core funding from the Australian Organ and Tissue Authority, New Zealand Health Te Whatu Ora, as well as Kidney Health Australia, ANZDATA published the 46th Annual ANZDATA Report (2022) on a wide range of statistics relating to incidence, prevalence and outcomes of treatment, of those with end-stage kidney failure. Analyses and reports published in 2023 also included: Individual Hospital Reports on data between 2017- 2022, which contain more detailed information about the characteristics and outcomes within each hospital; Dialysis and Transplant Centre Reports prepared for general distribution to the public; and Quality Indicator reporting to which Units use these data to monitor their clinical practice and outcomes.

The Registry team continued to expand in 2023, including practicing clinicians, epidemiologists, biostatisticians, researchers, project managers, clinical trialists, academics and consumers to further explore innovative ways to inform development of practice, policy and health services. With a focus on building strong relationships with consumers, the Registry also established a Consumer Advisory Panel, consisting of 11 individuals across Australia and New Zealand who have been impacted by kidney failure, are currently undergoing, or have received dialysis, have undergone a kidney transplant, or are caregivers, donors, or family members. Facilitated by a Patient Engagement Officer, the Registry also formed a Consumer Interest Register with approximately 16 members joining. These groups operate within a tiered approach to engagement, with the involvement of consumers in the Registry at various levels and stages to guide data collection, presentation of data and research efforts.

ANZDATA is also supported by a number of research grants and the various research programs conducted in 2023 are listed on the ANZDATA website <https://www.anzdata.org.au/anzdata/research/>. These are at varying stages of analyses and preparation for peer-reviewed publication and include, but are not limited to, pregnancy and parenthood, modelling future demand for kidney treatment, patient reported outcome measures, registry-based clinical trials, organ allocation, geospatial analyses, centre-specific reporting, quality indicator reporting, and data linkage.

The below highlights some of the research milestones achieved in 2023.

- A significant Registry and historic research moment was the publication of one of the Registry's first ever investigator-driven registry-based clinical trials, conducted across Australia and New Zealand. The BEST Fluids trial found that use of "balanced fluids", rather than saline as is currently used, reduced delayed graft function by 25%. This is a major improvement achieved by a very simple change to practice, yielding real benefits for patients. The research, led by Dr Michael Collins, was a collaboration between ANZDATA and the Australasian Kidney Trials Network (AKTN). While the BEST Fluids trial received funding from the Medical Research Future Fund in Australia, as well as the Health Research Council in New Zealand. the trial was incorporated within the usual workload of clinicians, thereby greatly reducing the costs and increasing the efficiency of the trial. Despite the challenges posed by COVID, the trial was completed ahead of schedule. The findings from the BEST Fluids study will change worldwide practice: Balanced fluids are relatively cheap and widely available, so will likely be used for most of the estimated 200,000 kidney transplant operations that are conducted each year across the globe.
- In collaboration with AKTN, the TEACH-PD Study (Targeted Education ApproaCH to Improve Peritoneal Dialysis Outcomes – Registry Based Trial) completed recruitment in 2023 with 1500 participants across Australia and New Zealand. This study is a pragmatic, multi-centre, multi-national, cluster-randomised

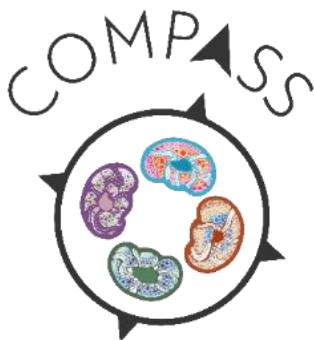
trial, randomising patients to implement TEACH-PD training modules targeted at PD trainers and incident PD patients versus standard existing practices.

- In partnership with the National Health and Medical Research Centre (NHMRC) Clinical Trials Centre, Prof. Rachael Morton and Prof. Stephen McDonald led a team of researchers and clinical trial coordinators in the SWIFT main study. SWIFT, or the Symptom Monitoring With Feedback Trial, evaluates the impact of symptom monitoring with feedback of results to clinicians on the quality of life for haemodialysis patients. This is measured by the validated and widely used EQ-5D-5L questionnaire, and the trial is in the final stages of recruitment. SWIFT has so far recruited over 1400 participants in NSW, QLD, SA and VIC, with NT and WA recruitment soon commencing.
- Led by A/Prof. Shilpa Jesudason, Program Lead, and Dr Erandi Hewawasam, Program Manager, the ANZDATA Parenthood Research group rebranded itself to the Pregnancy Kidney Research Australia (PKRA) in 2023. Linking data from ANZDATA with jurisdictional health and administration datasets, this research aims to support people with kidney disease to make informed choices about parenthood and achieve a successful pregnancy with the right care in place.

- The [National Indigenous Kidney Transplantation Taskforce \(NIKTT\)](#), a national, Commonwealth-funded project that aims to improve access to kidney transplantations for Aboriginal and Torres Strait Islander people in Australia, published a series of papers in the [Medical Journal of Australia](#) that highlight the work of the Taskforce and the progress that has been made to date on improving equity of access to transplantation. The NIKTT also received another 12 months of funding from the Department of Health and Aged Care to continue work on improving equity. The Taskforce, now a smaller four-person Secretariat based at SAHMRI, will focus on developing a data dashboard to track equity metrics across dialysis and transplant units, increasing the number of Indigenous Reference Groups at transplant units nationwide, and planning for the next five years of transplantation equity work through extensive consultation with Community and clinicians around the country.



NIKTT Secretariat in Canberra (L-R Kelli Owen, Assistant Minister for Indigenous Australians Hon Malarndirri McCarthy, Assistant Minister for Health and Aged Care Hon Ged Kearney, Stephen McDonald, Jaquelyne Hughes, Katie Cundale)



- MRFF-funded project COMPASS – Connecting Our Mob: Patient navigators As Sustainable Supports – ended 2023 on a high note, with nearly all patient navigators employed at sites in South Australia and the Northern Territory. COMPASS aims to coordinate patient navigators across the two jurisdictions that share one transplant unit, thereby making Aboriginal and Torres Strait Islander people living with kidney disease and seeking transplantation better able to navigate our complex kidney care systems.
- Utilising geospatial analyses, the burden of travel for patients receiving haemodialysis was examined. This involved adaptation of methodology to identify the “population centroid” of postcodes, and development of an API to interrogate Google Maps to calculate not just road distance but travel time at various times of day across these routes. This will underpin further work examining how proximity and access to services relates to the nature and outcome of treatment.

- Several large data linkage projects are approaching fruition. These involve linkage of ANZDATA with other Registries (Joint Replacement, Cardiac Surgery, Intensive Care). Initial results have been published from the Joint Replacement linkage, examining the rates and outcomes of hip and knee replacement for dialysis and transplant patients. For cardiothoracic surgery, early results have been presented at the ANZ Society of Nephrology and American Society of Nephrology conferences. As well as the individual research questions, these projects highlight the “value-add” from linkage of Clinical Quality Registry data in a strategic fashion, utilising established protocols to ensure privacy and security of data.

As a leader in clinical quality registries, ANZDATA continues to contribute and support the SAHMRI Registry Centre in 2023. ANZDATA actively collaborates, advise, and participates in major events across the clinical quality registry sector, including Clinical Registry Maturity Framework Survey, CQR Workshops and Annual Scientific Meeting Organising Committee, CQR Communication and Collaboration Hub and CQR Alliance of Registries.



Australia & New Zealand Eye Tissue Donation Registry (ANZETD)

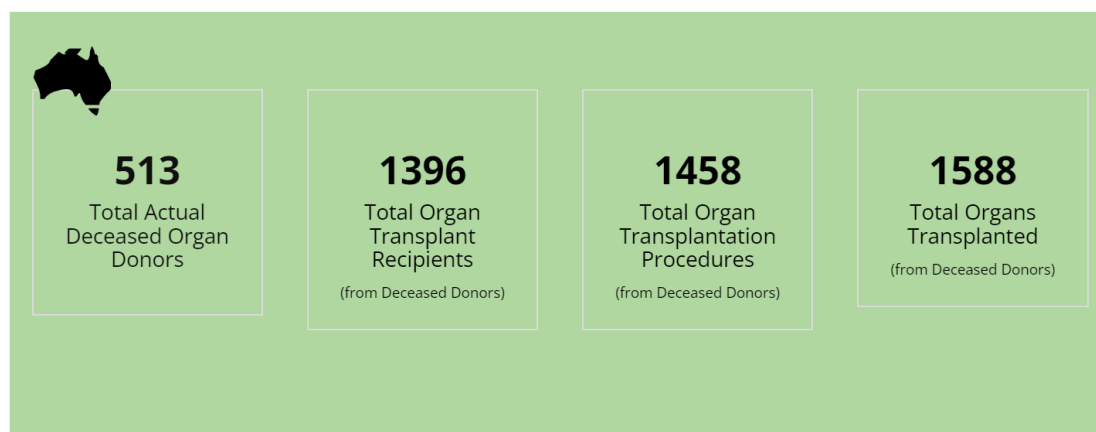
Work in 2023 continued to enhance the collaboration between the Eye Bank Association of Australia and New Zealand (EBBANZ), the peak body for eye donation and eye banking in Australia and New Zealand, the Australia and New Zealand Eye and Tissue Donation Registry (ANZETD) and the Australian Government Organ and Tissue Authority. Work continues with the sector to enhance the collection and reporting of eye and tissue donation and transplantation.



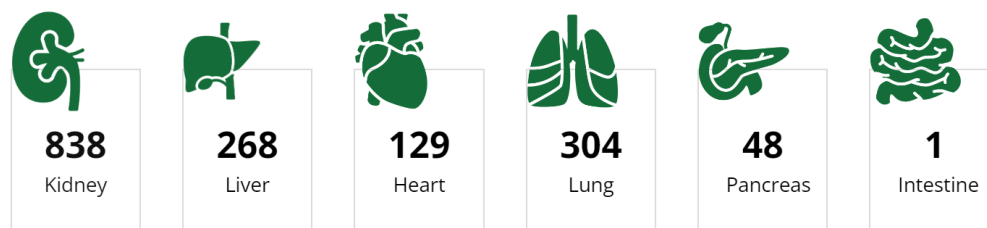
Australia & New Zealand Organ Donation Registry (ANZODR)

The Australia and New Zealand Organ Donation Registry (ANZOD) persists in gathering and documenting information on all activities related to organ, eye, and tissue donation. This data serves as the foundation for generating diverse statistics benefiting the local, national, and global communities. Throughout 2023, work continued to support the Australian Government Organ and Tissue Authority in establishing robust governance, oversight, and ongoing enhancements for the OrganMatch system. This tool aids clinicians in treating both transplant-awaiting patients and those who have undergone transplantation. As a crucial collaborator, ANZOD actively engages in advancing the requirements of the Transplant and Organ Donation sectors. In 2023 the ANZOD working Group was formed to review and expand the reporting outputs for ANZOD. This includes the formation of key collaboration groups with specific focus on areas of expertise and the commencement of work to expand the current ANZOD data collection.

Latest Donation Activity – 2023 Data Release



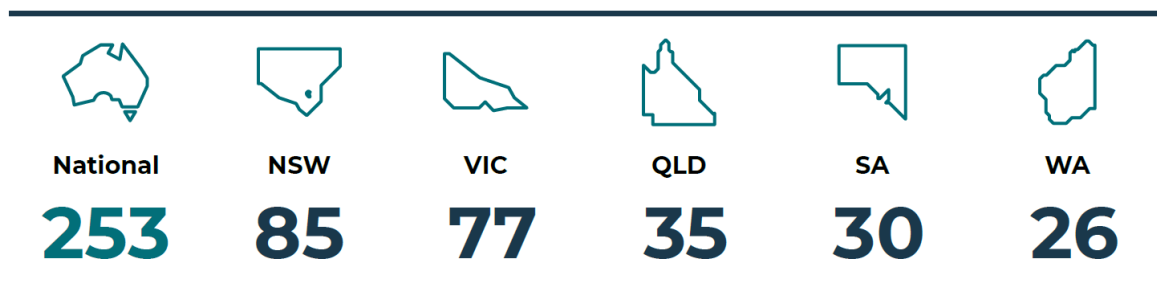
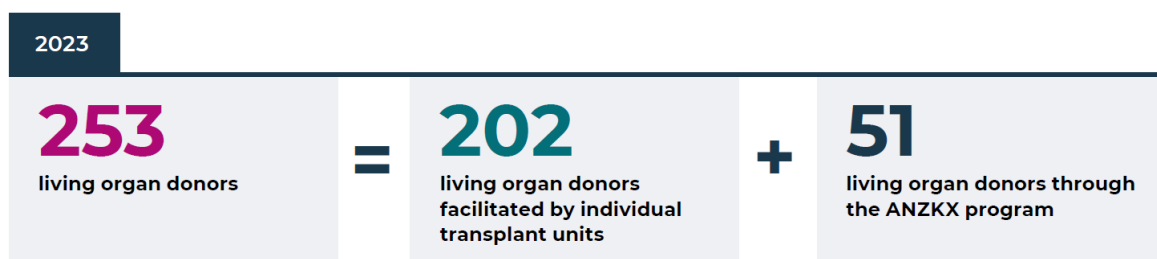
Total Organs Transplanted in Australia by Organ Type in 2023 (from Deceased Donors)



Australia & New Zealand Living Kidney Donation Registry (ANZLKD)

The Australia and New Zealand Living Kidney Donor (ANZLKD) Registry was established to provide information about the long-term health and well-being of people who donated a kidney for transplantation. Operating now for almost 20 years, within the auspices of the registry has been collecting data on living kidney donors across Australia and New Zealand. Data has been historically reported in the ANZDATA Annual Report in relation to living kidney transplantation.

In 2023, there were 253 living kidney donors in Australia. This result is 13% higher than the 2022 outcome of 224, and also surpassed the 2019 outcome of 239 donors by 6%. This outcome, and the trend over the last 4 years indicates that the sector is recovering from the impacts from the COVID-19 pandemic. The proportion of kidney transplants from living donors has varied over the last four years. While there was a reduction in 2020, there was a return to, or an increase on 2019 levels in most states by 2021. There continues to be variation across states with transplants from living donors accounting for 17% to 30% of total kidney transplants.



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

In Australia over the past four years, mothers were the most likely donor source for genetically related donors and wives the most likely source for emotionally related donors. The rates of paired exchange kidney donation remained stable, though the number of blood group incompatible transplants has decreased. For living donor characteristics, the proportion of people with hypertension increased in Australia from 2018-2022 compared with 2013-2017; other characteristics were largely unchanged.

In New Zealand Aotearoa, there were 78 living kidney donors. Although the of proportion living kidney donors for transplantation, remained stable, there is a greater proportion of living donors in NZ Aotearoa than in Australia. Over the past four years, in NZ Aotearoa, brothers were the most likely donor source for genetically related donors and wives the most likely source for emotionally related donors.



Australia & New Zealand Heart Transplant Registry (ANZHTR)

The Australian and New Zealand Heart Transplant Registry (ANZHTR) is a newly established registry that will operate as part of the wider group of organ donation and transplantation registries within the ANZDATA group. Along with ANZLUNG these registries serve to fill the void left when the previous Australia and New Zealand Cardiothoracic Organ Transplant Registry ceased operations in 2018.

Led by an advisory committee comprising clinical specialists from all heart transplant units across Australia and New Zealand, with collaboration from consumer representatives, this registry aims to become a robust platform for recording and reporting on heart transplantation.

Largely through the requirements of governance at all contributing sites, data collection is set to commence. Substantial efforts have been made to integrate data from the previous heart registry into ANZHTR, establishing a comprehensive longitudinal data repository.



Australia & New Zealand Lung Transplant Registry (ANZLUNG)

The Australian and New Zealand Lung Transplant Registry (ANZLUNG) is a newly established registry that will operate as part of the wider group of organ donation and transplantation registries within the ANZDATA group. Along with ANZHTR these registries serve to fill the void left when the previous Australia and New Zealand Cardiothoracic Organ Transplant Registry ceased operations in 2018.

Led by a steering committee comprising clinical specialists from all lung transplant units across Australia and New Zealand, with collaboration from consumer representatives, this registry aims to become a robust platform for recording and reporting on lung transplantation.

Largely through the requirements of governance at all contributing sites, data collection is set to commence. Substantial efforts from the lung transplant community will ensure the collaboration of historic data back to 1st January 2000 to ensure a comprehensive longitudinal data repository.



Australian Particle Therapy Clinical Quality Registry (ASPIRE)

In 2023, a significant milestone was achieved with the completion of the Australian Bragg Centre for Proton Therapy and Research (ABCPTR) building construction. Co-located within the Adelaide BioMed City precinct, alongside the Royal Adelaide Hospital, the new Women’s and Children’s Hospital, and the South Australian Health and Medical Research Institute. The ABCPTR brings advanced treatment options to patients requiring radiation therapy for solid tumours.

Installation and commissioning of the PBT treatment system will now take place, paving the way for patient treatments to commence. Anticipating a gradual ramp-up of services during the initial years of operation, ABCPTR stands at the forefront of cutting-edge medical technology.

The Australian Particle Therapy Clinical Quality registry - ASPIRE is a prospective, observational, longitudinal study of paediatric, adolescent and adult cancer patients from a select group of tumour types. The registry will initially describe the patterns of care for patients receiving photon radiation treatment. Once the ABCPTR is operational, this will also include those patients treated with PBT. The primary objective is to record the long-term side effects and disease control outcomes with a specific focus on the toxicity event types as described in the Medical Services Advisory Committee (MSAC) 1638 Public Summary Document.



Table 1 Summary of ranking of toxicity event types by cost offsets and QALYs averted across the adult population

Rank number	Population 1 (adult)	
	Cost offsets ranking	QALYs averted ranking
1	Visual impairment	Hearing loss
2	Mucositis	<i>Dysphagia</i>
3	<i>Xerostomia</i>	Endocrine dysfunction
4	Secondary malignancy	Visual impairment
5	Hearing loss	Mucositis
6	Endocrine dysfunction	Secondary malignancy
7	<i>Dysphagia</i>	<i>Xerostomia</i>

Italics text indicates a toxicity event type unique to that population.

Table 2 Summary of ranking of toxicity event types by cost offsets and QALYs averted across the paediatric/AYA population

Rank number	Population 2 (Paediatric/AYA)	
	Cost offsets ranking	QALYs averted ranking
1	Endocrine dysfunction	<i>Intellectual Disability</i>
2	Secondary malignancy	Hearing loss
3	Visual Impairment	Secondary malignancy
4	Mucositis	Endocrine dysfunction
5	Hearing loss	Visual Impairment
6	<i>Intellectual Disability</i>	Mucositis

Italics text indicates a toxicity event type unique to that population.



MSAC 1638 Public Summary Document

Following the Cancer Australia report, August 2023 - “Strategy for Proton Therapy for cancer patients in Australia”, the ASPIRE protocol was amended and received governance approval to collect data on additional tumour streams at the Royal Adelaide Hospital site, including left-sided breast cancer, head and neck, and esophageal cancer. This expansion aims to provide evidence for future Medical Services Advisory Committee applications to extend PBT indications for subsidy.

An ASPIRE National Steering Committee has been established. The committee comprises a diverse range of members, including consumer advocates, representatives from TROG Cancer Research and The Hospital

Research Foundation Group, as well as clinical experts with multidisciplinary backgrounds in the field of radiation oncology from various Australian states and territories.

Following a formal expression of interest, the national roll-out strategy, as voted on by the National Steering Committee has progressed with potential partner institutions at various stages of site-specific approvals. Approval and subsequent recruitment is anticipated at the following institutions throughout 2024/2025;

- Alan Walker Cancer Care Centre
- Sydney Children’s Hospital
- Monash Children’s Hospital
- Sir Charles Gairdner/Perth Children’s
- Royal Brisbane & Women’s Hospital.

This phased approach ensures a systematic and thorough expansion of the collaborative research network, contributing to the national success of the registry initiative.

Future goals for the registry include Patient Reported Outcomes Measures (PROMS) and Quality of Life participant surveys in collaboration with the University of South Australia. This initiative will contribute to robust survivorship data collection, including a feasibility study for a survivorship program at the ABCPTR.

In summary, the past year has seen significant progress in the establishment and expansion of the ABCPTR and ASPIRE, positioning Australia at the forefront of 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 (BQA)

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. Surgeons can self-assess their clinical performance against set key performance indicators (KPIs). Research into breast cancer treatment and outcomes using de-identified audit data forms an important part of the audit's value. Breast Surgeons of Australia and New Zealand require members to submit data on all cases of early and locally advanced breast cancer.

In 2023,

- the BQA relaunched new data fields and KPIs.
- released the BQA Annual Report and distributed it to the BreastSurgANZ community.



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

The ANZELA-QI project, modelled after the National Emergency Laparotomy Audit (NELA) in the UK, initiated an Australian emergency laparotomy audit and clinical quality registry (CQR) as a national continuous improvement effort. The registry collects near real-time data on emergency laparotomy, driving improvements in individual patient care by assessing compliance with evidence-based standards.

Nationally in 2023, participation increased from 12 pilot hospitals to 47, documenting 10,157 eligible cases. Enhanced REDCap functionality was achieved by developing an external module for REDCap with real-time data quality checks, significantly reducing missing data. ANZELA-QI staff contributed to the development of the external module, which was approved for wider use within the REDCap community. The new look database was launched in July 2023 and has so far received positive feedback from users.

Automation of data collection, exemplified by Alfred Health's success, streamlined processes, and increased case identification by 30% compared to manual methods. This was a collaborative effort between Monash University, and the Departments of Surgery and Anaesthesiology and Perioperative Medicine at Alfred Health. Fiona Stanley Hospital is progressing towards automated data collection, aiming to mirror Alfred Health's achievements. The 2022-2023 ANZELA-QI National Report, focusing on Delays, will be published by mid-2024.



Australasian Registry of ECGs of National Athletes (ARENA)

The Australasian Registry of Electrocardiograms in National Athletes (ARENA) was launched in November 2023. ARENA will collect and centralise cardiac screening data from sporting organisations to facilitate current and future research. Initial data collection will be in Australia, with the intention to expand to New Zealand. It is led by researchers at the University of Sydney, in collaboration with other national and international experts and based at the SAHMRI Registry Centre. ARENA has been endorsed by The Australasian College of Sport and Exercise Physicians and Sports Medicine Australia.

ARENA is working closely with participating sporting organisations, which will be able to use this registry to improve the quality of their cardiac screening programs and provide better cardiac care for young athletes. Data collection will include retrospective and prospective cardiac screenings. Ethical approval was received from the University of Sydney Human Research Ethics Committee in October 2023 (Project No. 2023/551).

Sudden cardiac death (SCD) in athletes is a rare but tragic event. Cardiac screening of elite athletes for conditions associated with SCD is now widely recommended by leading bodies such as the Australasian College of Sport and Exercise Physicians (ACSEP). Screening generally includes a personal and family history and a physical examination, together with a resting 12-lead electrocardiogram (ECG).

However, while many Australian and New Zealand sports are screening athletes, data are not structured to be shared, meaning few comparisons exist across different sports. In addition, diverse ethnic groups and female athletes are under-represented in research that informs current guidelines.

ARENA is a registry that brings together athlete screening data and ECGs collected in Australasia. All elite sports conducting cardiac screening of athletes (including ECG) are eligible to provide data. ARENA works closely with participating sporting organisations, which are able to use this registry to improve the quality of their cardiac screening programs and provide better cardiac care for young athletes.

ARENA aims to provide long-term national data to improve our understanding of:

- The role of various ethnicities, age and sex in terms of accurate athlete ECG interpretation
- The bounds of normal cardiac adaptations to exercise across athletes from different Australasian sports to provide relevant benchmarks for normal athlete ECG features and accurate interpretation
- Outcomes of screened athletes





● **DISEASE OR CONDITION REGISTRIES**

SA Cerebral Palsy Register (**SACPR**)

SA Birth Defects Register (**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

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.

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 has an ongoing commitment to contributing non-identified data to The Australian Institute of Health and Welfare, as part of the recently re-established national congenital anomalies collection. This data has been included in a number of web-based reports. Based on data from 7 jurisdictions across Australia, the latest report presents final data on congenital anomalies for the 2016 and 2017 birth cohorts and preliminary data for the 2018 birth cohort. The 2019 birth cohort preliminary report is expected to be released sometime in 2024.

During 2023, a focus for the team was the introduction of the Sunrise Electronic Medical Records system and using this system to establish new and different ways to source information relating to congenital anomalies.

The SABDR contributed to multiple research projects in 2023, including studies on congenital heart anomalies, and screening in pregnancy for anomalies.

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 2023, the latest annual SACPR report was published, presenting information for children with cerebral palsy born in the years 1993-2017. 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 1.70 per 1,000 live births (2015-2017). 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.

During 2023, a focus for the team has been the introduction of alternative ways for families to provide their consent to participate in the SACPR. We now offer multiple ways for families to engage with the register, including returning a hard copy consent form via prepaid envelope or in person, emailing us a photo or scan of the signed form, or scanning a QR code to take families to the SACPR website, where they can complete their consent form online.

The SACPR contributed to a number of different research projects in 2023, including providing assistance with recruitment to studies, and providing non-identified data as part of linkage projects.



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

ANZVASC-QDR is a new registry that enrolled its first participant in August 2023. We are a national registry that also includes New Zealand, based at Monash University, and we thank the SAHMRI Registry Centre for inviting us to be part of the group. Most of 2023 has been spent (as was 2021 and 2022) setting up the registry. Establishing a vasculitis registry is one of the key aims of the Australia and New Zealand Vasculitis Society (ANZVASC).

The current registry can cater for all types of vasculitis but is oriented towards ANCA-associated vasculitis and large vessel vasculitis. It has several purposes, including the provision of clinical quality data to participating units to help improve care and outcomes, enabling and supporting vasculitis research, and being a platform for registry linked clinical trials and surveillance of new therapies and practices. Monash University is of necessity the data custodian, with the ANZVASC Registry Committee developing policies, providing input and advice via the ANZVASC Board.

The first 6 registry sites, specifically Monash Health, Central Adelaide Local Health Network [Royal Adelaide and The Queen Elisabeth Hospital], The Prince of Wales Hospital, Southwestern Sydney Local Health District and Auckland Hospital have HREC approval and are completing governance. An EOI for further sites will be advertised in 2024, subject to funding. The registry uses an opt-in model, with initial data entry and a short yearly follow up, with the option of additional entries. It includes validated Patient Reported Outcomes. As of mid-November 2023, there are over 100 participants enrolled. We look forward to 2024 and beyond as we establish and expand the reach of the registry.



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 this registry project is to identify the most effective management approaches.

In 2023, the Registry Study Group published its first research report in *Ophthalmology Retina*. This article was published open access for maximum circulation. We reported clinical features and management of 80 women and men patients presenting with vitreoretinal lymphoma between January 1, 2020 and December 31, 2022. One important finding was the level of visual impairment experienced by patients. Overall, 60% of patients had some degree of visual burden, defined on impairment in one eye, and 20% had visual burden defined on impairment in both eyes. Another key finding was the common use of ocular therapeutics, with strong bias toward intraocular chemotherapy with methotrexate. The published results were presented at an international meeting: the Pan-American Society of Inflammatory Ocular Diseases Meeting, held in San Francisco, United States in November 2023.

At the end of 2023, we were awarded a 3-year research grant for the registry project from Tour de Cure, partnering with Queensland Eye Institute Foundation and Flinders University. One additional partner is the International Ocular Inflammation Society, which includes a large group of clinicians around the world who diagnose and treat vitreoretinal lymphoma.

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. What initially began as a pilot program at the University of Western Australia in 2001 has been rolled out across all Australian states and territories under the governance of the Royal Australasian College of Surgeons (RACS) and with support from local departments of health. Through the participation of surgeons ANZASM is able to collect clinical and demographic data on patient in-hospital mortality, as well as data on subsequent evaluation of the surgical management of these patients. This places ANZASM in a unique position to provide critical yet constructive feedback to practicing surgeons, participating hospitals and Departments of health. 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 March 2020, ANZASM had facilitated the review of 34,311 instances of patient in-hospital mortality where surgical care was involved (since its inception), with a further 5,748 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 56.7% male and constituted emergency presentations with an acute life-threatening condition in 85.4% of cases. In terms of risk profile, 92.2% of patients presented with an ASA score (American Society of Anesthesiologists physical classification system) of 3 or higher, with 89.1% of patients having at least one comorbidity. Following independent review, it was considered that in 23.9% of cases clinical management could have been improved, with delays to intervention and operative management issues being the two main areas of complaint.

The independent evaluation of these cases has enabled ANZASM to identify particular areas of surgical management to target in order to improve patient outcomes, including avoiding futile surgery (and appropriate consideration of palliative care), the importance of early consultant engagement for complex cases and the beneficial impact of non-technical skills for patient welfare.



Royal Australasian College of Surgeons

**Australian and New Zealand
Audits of Surgical Mortality**

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

SA-PCCOC had an eventful year in 2023 navigating funding hurdles, continuation of data access, and an increasingly complex governance environment.

Despite challenges, the team has maintained excellent recruitment rates with the registry now holding data on over 22,000 men diagnosed with prostate cancer.

The team has made enormous efforts to prepare to change data platforms which is scheduled to take place in early 2024.

SA-PCCOC contributed to a consumer forum on prostate cancer held at Flinders Medical Centre in 2023; and co-hosted the 2023 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 research output with 13 papers in 2023 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.

The registry acknowledges generous support from the Movember Foundation, The Hospital Research Foundation, Freemason's Centre for Male Health and Wellbeing and the Urological Society of Australia and New Zealand.



Australian and New Zealand Registry of Advanced Glaucoma (ANZRAG)

The Australian and New Zealand Registry aims to identify novel genetic risk factors for glaucoma blindness and has recruited 9203 individuals over the past 16 years. The recruitment is ongoing with an additional 573 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, Disc Drusen, Nanophthalmos, and early stages of Glaucoma.

The most prevalent participants were Advanced Glaucoma (39%), followed by Non-Advanced Open-Angle Glaucoma (24%).

There are 478 specialists from across Australia and New Zealand who have referred participants to ANZRAG.

Participants from every state and territory, including New Zealand, United States, Cambodia, and the UK have been recruited and provided a DNA sample in 2023.

In 2023 ANZRAG expanded to include additional sites at the Queen Elizabeth Hospital (QEH) and Royal Adelaide Hospital (RAH) to increase the number of underrepresented ancestry groups from the Australian population. In addition, recruitment has begun for those participants currently not affected by Glaucoma (Controls) to develop and validate a polygenic risk score (PRS) in all Australian ancestry groups.

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, which led to two publications (publications 1-2) since 2022.

5032 individuals have been screened for the MYOC gene (the most common gene associated with adult-onset glaucoma) and 173 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.

Publications:

1. Marshall HN*, Hollitt GL*, Wilckens K, Mullany S, Kuruvilla S, Souzeau E, Landers J, Han X, MacGregor S, Craig JE, Siggs OM. (2022) High polygenic risk is associated with earlier trabeculectomy in primary open-angle glaucoma. *Ophthalmol Glaucoma*. In Press. doi:10.1016/j.ogla.2022.06.009
2. Hollitt GL, Siggs OM, Ridge B, Keane MC, Mackey DA, MacGregor S, Hewitt AW, Craig JE, Souzeau E. Attitudes Towards Polygenic Risk Testing in Individuals with Glaucoma. *Ophthalmol Glaucoma*.2022 Jul-Aug;5(4):436-446. doi: 10.1016/j.ogla.2021.11.002. Epub 2021 Nov 11. PMID: 34774858.



AUSTRALIAN & NEW ZEALAND
REGISTRY OF ADVANCED GLAUCOMA

Australian Corneal Graft Registry (ACGR)

The Australian Corneal Graft Registry continued strongly in 2023, with more than 2,000 additional grafts registered. The database now contains over 46,000 registered corneal transplants in almost 32,000 individual graft recipients. 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 almost 5,500 grafts during 2023. Linkage with the National Death Index facilitated the update of more than 5,000 further records. The longitudinal nature of the ACGR is one of its greatest strengths and 187 grafts have now been followed for more than 30 years, with 20 grafts stretching to over 35 years.

The importance and usefulness of the ACGR in providing individual audits to surgeons and eye banks was highlighted at the Royal Australia and New Zealand College of Ophthalmologists Congress in 2022. Up-to-date audits were provided to all contributing surgeons with 20 or more grafts of a specific type registered with the ACGR by September 2023. These analyses provided detailed information to surgeons regarding benchmark results for cohorts that are similar to their own in terms of graft type, era of graft, and indication for graft. This information can play an important role in surgeons' continuing professional development.

In partnership with several contributing surgeons, a journal article titled "Comparison of penetrating and endothelial keratoplasty in patients with iridocorneal endothelial syndrome: A registry study" was published in *Clinical and Experimental Ophthalmology*. 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. Two annual reports were produced in 2023. An interim report to contributors was presented at the annual Australia and New Zealand Corneal Society Meeting held in Perth in March. A further written report, summarising the data contained in the ACGR database as of 30th June 2023, 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 was established in 2020 and is the first of its kind in Australia, and includes patients diagnosed and treated for kidney cancer and related kidney health issues within the last 20 years at Flinders Medical Centre, Noarlunga Hospital or the Repatriation General Hospital.

Currently it has information of more than 600 patients and is expanding to include patients treated at other South Australian public hospitals, with the hope of further expansion nationally. Northern Adelaide Local Health Network (NALHN) will be officially added as an additional site for the registry in 2024.

Using data from the Registry, innovative research projects are underway which include – assessment of the quality of life of people who have undergone nephrectomy, development of a score to predict risk of developing chronic kidney disease after nephrectomy, assessment of the outcomes of different methods of managing small renal masses/cancer and renal cysts.

In 2023, the registry joined the SAMRI Registry Centre and has also been able to craft its first newsletter which will be circulated shortly to all the patients. Also, the work done by the Registry was presented to the Hon. Mark Butler MP, Minister for Health and Aged Care, Hon Rebekha Sharkie MP, Federal member for Mayo, Hon Louise Miller – Frost MP, Federal member for Boothby and Hon Dan Cregan, Member of Kavel on different occasions.

To summarise the Registry is expanding to other health networks and gaining attention from the public which would ultimately help doctors and families to make more informed decisions on what treatment will work best for an individual patient, improve outcomes and create a brighter future for people with kidney cancer and related kidney health issues and their families.





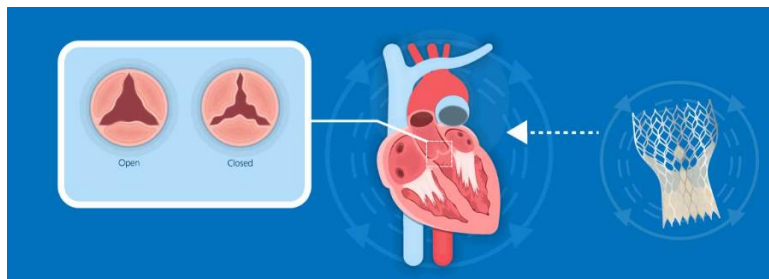
● **PRODUCT REGISTRIES**

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

Transcatheter Aortic Valve Implantation (TAVI-R)

Registry

The Transcatheter Aortic Valve Implantation Registry (TAVI-R) is a clinical quality registry supported by the Australasian Cardiac Outcomes Registry (ACOR) Ltd as part of quality control and monitoring of procedural and clinical outcomes of patients undergoing aortic valve replacement via a transcatheter approach. Since the TAVI-R commenced (2018) the Registry has seen significant uptake.



In 2023 the Registry:

- Saw the commencement of an additional 4 data contributing sites bringing the national total to 52 sites,
- Saw data collection reaching close to 19,000 TAVI cases,
- Conducted a pilot source data audit across four (4) NSW sites to assess case completeness,
- Continued ongoing improvements in the management of data collection, reporting and ad-hoc data request provision.
- Individualised reports were prepared and sent to 51 hospitals and 111 operators who undertake TAVI procedures. These reports provided information on case-mix and adverse events at 30 days and 12 months.

The TAVI-R remains:

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

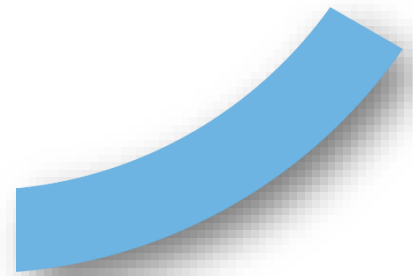


Dental Implant Registry (DIR)

The DIR reached several important milestones and events in 2023.

The DIR's strategic goals from its inception were to initially develop a register for dental implant devices, then move to development of an implantable device registry, facilitating scientific research around these devices in non-academic/clinical settings.

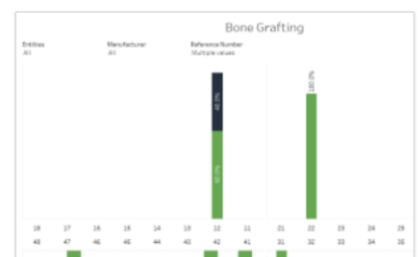
The DIR has now achieved Ethics approval for its registry activities and is moving to complete an entire overhaul of reporting systems available in real-time to participating clinicians, industry partners, device manufacturers, associated industry bodies and regulators.



Implant Reports
yesterday



Patient Reports
yesterday



Bone Grafting
yesterday



The DIR also reached 9000 devices registered with the registry and the highest monthly registration of devices in the last quarter of last year.

Developments in our web application also allow more detailed data around bone grafting protocols and bone graft material usage in participating clinicians.

We have also made progress in our overseas market strategies in providing our web application for use in other countries. The diversification of data will be extremely interesting as we are aware of significant differences in surgical and prosthetic protocols and devices used in other countries.

The DIR is now in the process of developing our scientific board and team to move the important tasks of data analysis of the current AU/NZ data and start producing important market feedback to health care professionals and the device supply chain. We are also keen to improve on our patient advocacy group activities in 2024.





REGISTRY CENTRE
A CENTRE OF EXCELLENCE FOR
REGISTRIES AND REGISTRY SCIENCE



ABN: 54 141 228 346

SAHMRI North Terrace, Adelaide SA 5000

P +61 (0)8 8128 4000
E reception@sahmri.com

PO Box 11060, Adelaide SA 5001

www.sahmri.org.au

Follow us on: www.facebook.com/sahmri www.twitter.com/sahmriAU

