

SAHMRI Registry Centre

Annual Report 2022



Letter from the Executive Director - Professor Steve Wesselingh

The South Australian Health & Medical Research Institute, Registry Centre was established in 2018 to strengthen the voice of participating registries within the centre in the national registry field and expand our individual and coordinated capacity, reach, and influence in this and other important areas.

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

The Centre brings together some of Australia's most significant registries based in South Australia, to share their expertise in registry science, operations, community and stakeholder engagement, dissemination activities, and evidence translation into clinical practice and policy.

By leveraging the skills, expertise and resources of its member registries, the Centre provides for increased quality, efficiency and cost effectiveness of certain registry operations, while enhancing the capacity of registry leads, staff, and researchers, both within and external to SAHMRI. Ultimately the Centre hopes to facilitate driving improvements in the quality of care and health outcomes for all Australians, especially those covered by our 18 Centre member registries. In early 2022, through a collaborative funding arrangement between SAHMRI, ANZDATA and ROSA, SAHMRI appointed Cindy Turner as our Strategic Director to provide oversight and lead the development of the Centre.

Throughout 2022 we hosted the ACTA Annual Scientific Meeting, including the inaugural Australian Registry Annual Scientific Meeting, the Registry Centre Workshop and a series of eight educational forums. As we look forward to 2023-24, the Centre is working to operationalise how it can become the platform to enhance the enormous value of registry data, supporting the utilisation of other important data sources such as trials, surveys, biobank data, administrative data sets and information systems, through data linkage and research collaborations.

In this report we are presenting a snapshot of 2022 and a glimpse into the work of the registries who form the Centre.

Thank you to all the Registries and the Registry Centre Executive Team for your continued support, we look forward to the continuing development of this important work.

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HEALTH SERVICES REGISTRIES

- Registry Of Senior Australians (ROSA)
- Australia & New Zealand Dialysis & Transplant Registry (ANZDATA)
- Australia & New Zealand Organ Donor Registry (ANZOD)
- Australia & New Zealand Eye Tissue Donation Registry (ANZETD)
- Australia & New Zealand Living Kidney Registry (ANZLKD)
- Australian Corneal Graft Registry (ACGR)
- BreastSurgANZ Quality Audit (BQA)
- ANZ Emergency Laparotomy Audit – Quality Improvement (ANZELA-QI)
- Australian Particle Therapy Clinical Quality Registry (ASPIRE)

DISEASE OR CONDITION REGISTRIES

- SA Cerebral Palsy Register (SACPR)
- SA Birth Defects Register (SABDR)
- International Vitreoretinal B-cell Lymphoma Registry (IVRLR)
- Australian and New Zealand Audit of Surgical Mortality (ANZASM)
- South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC)
- Australian and New Zealand Registry of Advanced Glaucoma (ANZRAG)

PRODUCT REGISTRIES

- Transcatheter Aortic Valve Implantation (TAVI)
- Dental Implant Registries (DIR)

Letter from the SAHMRI Registry Centre

Strategic Director - Cindy Turner

I am delighted to present the first SAHMRI Registry Centre Annual Report. As a developing Centre for Excellence for Registries and Registry Science, it has been a busy and productive year spent creating a strategic plan for the Centre, identifying key elements short term and long-term interest for the Centre, and consolidating and formalising the network of the Centre. Thank you all for your time and support thus far in this initial phase of our Centre development.

Registries that form the SAHMRI Registry Centre (the Centre) encompass a broad range of health topics covering many of the National Health Priority Areas. The Centre registries include the areas of aged care quality and safety, cancer, cardiovascular conditions, musculoskeletal health, kidney dialysis, organ transplant, spinal injuries, cerebral palsy and other birth defects, and many other health issues.

It was timely to begin 2022 with a review of the governance of the Centre. This review resulted in the development of the SAHMRI Registry Advisory Group, on which all member registries have a representative, and a revised Terms of Reference which now sees the Centre well positioned for future development. The Centre supports the collaboration of member registries by working together and supporting development in the registry sector. Our strength as a group enables us to contribute at a national level to important sector-level consultations and we welcome the support and positive working relationships formed with the Australian Department of Health and Aged Care and the Australian Commission on Safety and Quality in Health Care (ACSQHC).

Of great interest to the Centre and our member registries is the development of a sustainable registry science sector which includes the frameworks we operate within and the development of sustainable funding models. Registry Centre members see this an important area of advocacy that the Centre can support. More sustainable funding for registries will free up existing resources to concentrate on the core aspects of registry work and reduce the resource drain that results from the need to continually seek funding for core activities. Sustainable funding models allow registries to mature, increasing their connection and interactions with the health system and support the development of advanced reporting capabilities. We look forward to the development of the registry science sector and the opportunity to address these important issues.

This year as a Centre, we have also been exploring the concepts of interoperability and integration with health services. The role of registries in this important area of future development in the Australian digital health space is yet to be fully determined. Many registries have had limited resources to undertake the significant amounts work required to progress this concept. To further explore these concepts, the Annual

Symposium in March 2023 is themed 'Enhancing the Capability of Clinical Registries – Integration/ Interoperability with health systems.

We have been fortunate this year to connect with My Health Record Section - Digital Health Branch of the Australian Department of Health and Aged Care, as well as the Multi-Agency Data Integration Project (MADIP) - Australian Bureau of Statistics, both agencies are informing our learning and building our knowledge of how to support member registries build capacity for interoperability and integration into the future.

As a Centre, we have contributed to the consultation on Secondary Use (research) of My Health Record data, the Australian Commission on Safety and Quality in Health Care (ACSQHC), Framework for Australian clinical quality registries – Second Edition, and the Healthcare Identifiers Framework Project Consultation.

The launch of the ACSQHC Framework for Australian clinical quality registries second edition, presented an ideal opportunity for the Registry Centre to have input into this important document to help guide the future direction of national clinical quality registries in Australia.

In addition to these important national collaborations and relationships, the Registry Centre is building connections at a jurisdictional level in South Australia.

Our representation on the Australian Clinical Trials Alliance (ACTA), Special Interest Group for Registries, continues to be an important avenue of advocacy for member registries and the sector.

I would like to take this opportunity to welcome new registries who joined the Centre in 2022:

- International Vitreoretinal B-cell Lymphoma Registry (IVRLR)
- Australian Particle Therapy Clinical Quality Registry (ASPIRE) Australian Bragg Centre SA

The Registry Centre and member registries have a busy year planned for 2023 and we are looking forward to being part of, and contributing to, the vibrant and growing sector of registry science in Australia.

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 as trials, surveys, biobank data, administrative data sets, and information systems, through data linkage and research collaborations.

AIMS

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

GOVERNANCE

A Collaborative funding arrangement between South Australian Health and Medical Research Institute (SAHMRI), Australia & New Zealand Dialysis & Transplant Registry (ANZDATA) and the Registry of Senior Australians (ROSA) supports the SAHMRI Registry Centre.

The SAHMRI Registry Centre Strategic Director works closely with the SAHMRI Executive Director, SAHMRI Registry Centre Advisory Group, and SAHMRI-based Registries on the activities of the 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*

Professor Steve Wesselingh	SAHMRI
Cindy Turner	SAHMRI Registry Centre
Professor Maria Inacio	ROSA
Professor Stephen McDonald	ANZDATA
Kelly Marshall	ANZDATA
Kylie Hurst	ANZDATA
Anita Deakin	TAVI
Emma Heath	SAHMRI / TAVI
Dr Miriam Keane	ACGR
Damian Cortviend	DIR
Dr Catherine Gibson	SABDR, SACPR
Heather Scott	SABDR, SACPR
Kelly Skelton	ASPIRE
Dr Michael O'Callaghan	SA-PCCOC
Karen Hall	ANZRAG
Justine Smith	IVRLR
Lora Papa	ANZASM, BQA, ANZELA-QI
Professor David Roder	Cancer Population Registries
Dr Rosanna Tavella	University of Adelaide (guest)
Helen Thomas	Wellbeing SA
Shyamsundar Muthuramalingam	Consumer Engagement

**Representatives may change throughout the year*

Registry Centre Activities

Australian Registry Annual Scientific Meeting

SAHMRI was delighted to host the ACTA Annual Scientific Meeting 2022, including the inaugural Australian Registry Annual Scientific Meeting in the SAHMRI auditorium in November 2022. The theme for this event was: **The Value of Registries in Challenging Times.**



This important event brought together Australian Registries, as well as governments, not for profits and other funders, clinicians and health services.

After the impact of COVID and an inability to meet

face to face the opportunity to bring people together and participate in the Australian Registry ASM was very exciting and rewarding. The energy and commitment within the Registry Sector was evident and the quality of presenters was high. Feedback from the nearly 140 attendees was extremely positive, and we look forward to seeing this event grow and develop further in the future.

2022 Registry Centre Workshop

Whilst COVID limited our capability to deliver the number of activities as in previous years, in September 2022 the Registry Centre was delighted to present Professor Michelle Dowsey on the topic of 'The Value of Institutional Registries for Informing Clinical Practice. Michelle established the St. Vincent's Melbourne Arthroplasty (SMART) Registry, which has captured



all hip and knee replacement procedures at St. Vincent's Hospital, Melbourne since 1998. SMART currently houses over 12,000 procedures, more than 150,000 patient outcome surveys, and has informed publications, competitive grant applications and guideline development. Michelle's presentation was well received, and we look forward to being kept up to date on the work and achievements of institutional registries such as the SMART Registry.

Statistical Education Forums

The Centre was able to offer member registries a series of eight educational forums throughout 2022, with attendances ranging from 19 to 24 individual per session with an increasing number joining the invitation list throughout the year. A brief evaluation and feedback survey completed at the end of 2022 indicates that attendees found the sessions exposed them to new analytical methods, were useful and interesting and that the forums provided connections to others working in the Registry Science Sector. Many thanks to Dr Chris Davies, Lead Biostatistician at ANZDATA Registry for coordinating these sessions, we look forward to these continuing throughout 2023.

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

One of the priority actions under pillar 1 of the National Clinical Quality Registry and Virtual Registry Strategy 2020-2030 is to build capacity within registries in engaging patients, their carers, families, and consumer organisations in the co-design of data requirements that measure outcomes that matter most to them and reflect their lived experience. Registries within the SAHMRI Registry Centre undertake consumer engagement activities, with some registries already in

a mature phase and others in the initial stages of consumer engagement. To bridge the gap and promote collaboration on consumer engagement activities and to create a shared learning environment for registries, the **SAHMRI Consumer Engagement Community of Practice** (SAHMRI CE CoP) was established in 2021 by ANZDATA in collaboration with Health Translation SA. The Consumer Engagement Community of Practice's primary objective is to support registries in launching their consumer engagement work or to maintain the efforts already begun.



The Annual Consumer and Community Engagement Summit which was hosted by SAHMRI in 2021 and 2022 welcomed more than 50 consumers, community members, researchers and health professionals.

2023 Registry Centre Symposium

The Registry Centre is busy planning its Annual Symposium March 24, 2023, with a theme of 'Enhancing the Value of Registries – Interoperability and the Integration of Registry Data within Health Systems'.

The symposium will coincide with the release of this report and is shaping up to be an exciting event with international speaker Professor Daniel Prieto-Alhambra, Professor of Pharmaco- and Device Epidemiology,

NIHR Senior Research Fellow, CSM-DORMS, University of Oxford, followed by an impressive array of National and South Australian presenters and researchers:

- Dr Bernadette Aliprandi-Costa, Australian Commission on Safety and Quality in Health Care
- Ms Siobhan McFadden and Mr Chadi Tahan - My Health Record + Australian Digital Health Agency
- Dr Alexander Hanysz – Australian Bureau of Statistics, Multi Agency Data Integration Project (MADIP)
- Dr Santosh Verghese – South Australia Health
- Dr Janet Slugget – Registry of Senior Australians ROSA
- Dominic Keuskamp – Australia & New Zealand Dialysis and Transplant Registry ANZDATA
- Ms Mikaela Doig – Australian Particle Therapy Clinical Quality Registry ASPIRE
- Dr Tesfahun Eshetie – Registry of Senior Australians ROSA
- Dr Erandi Hewawasam – Australia & New Zealand Dialysis and Transplant Registry ANZDATA
- Ms Emily Duncanson – Australia & New Zealand Dialysis and Transplant Registry ANZDATA
- Ms Melanie Penfold – Australian Particle Therapy Clinical Quality Registry ASPIRE
- Dr Emmanuelle Souzeau – Australia & New Zealand Registry of Advanced Glaucoma ANZRAG
- Professor Stephen McDonald - Australia & New Zealand Dialysis and Transplant Registry ANZDATA
- Professor Maria Inacio - Registry of Senior Australians ROSA

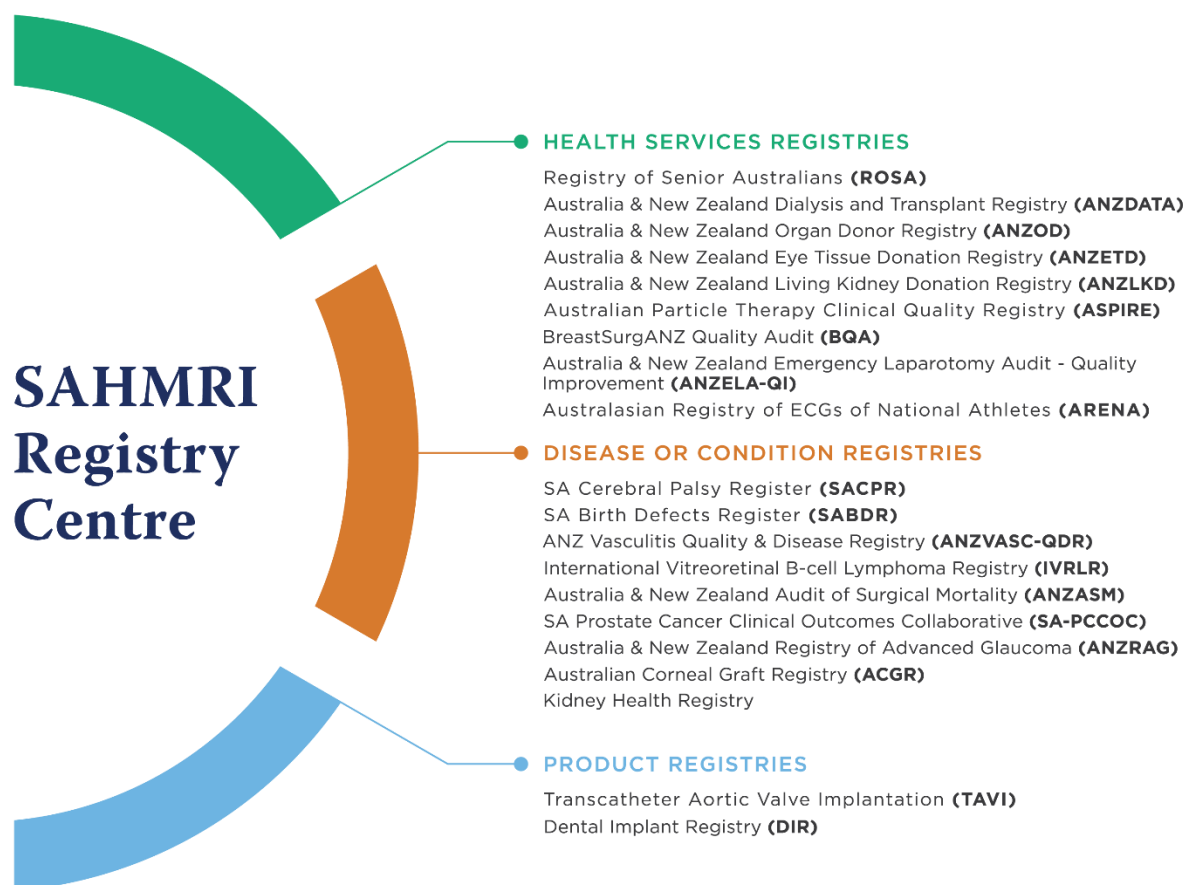
Summary

In this and future reports we hope to provide an outline of the purpose and aims of the Registry Centre and include a snapshot of planned future directions. This report also clearly outlines our governance structure and membership of the Advisory Group.

The report presents the activities of the Centre over the past 12 months, including workshops and educational sessions, we are especially pleased to have been able to contribute to a number of national consultations to facilitate driving improvements in the quality of care and health outcomes for all Australians.

We are delighted to present highlights of the work of member registries over the previous year in the following pages and encourage you to contact the individual registries if you have research projects or questions in their areas of clinical interest.

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**)
- Australian Particle Therapy Clinical Quality Registry (**ASPIRE**)
- BreastSurgANZ Quality Audit (**BQA**)
- Australia & New Zealand Emergency Laparotomy Audit - Quality Improvement (**ANZELA-QI**)

Registry Of Senior Australians (ROSA)

The Registry of Senior Australians (ROSA) is an Australian Clinical Quality Registry 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 2022, the ROSA team published 16 academic studies and delivered three commissioned reports to the federal government to support national ongoing Aged Care Reforms.



The team was awarded a MRFF Dementia, Ageing, and Aged Care Mission grant to establish the national consortium Australian Consortium for Aged Care Quality Measurement Toolbox (QMET) project, which will work to deliver a national framework to examine quality of care for older Australians across care settings. ACAC's Coordinating Centre will be based with ROSA until 2027. The team also had other grant success, with Dr Janet Sluggett being awarded a NHMRC Investigator Grant to continue her work evaluating the quality use of medicines in older people in residential care and upcoming reforms to improve medication management and Dr Tesfahun Eshetie was awarded a SAHMRI seed grant to develop new methods to examine deprescribing in the ROSA dataset.

The team also received four awards recognising their achievements, including the SAHMRI 2022 Research Translation and Impact Award for the team and SAHMRI Mid-Career Researcher Award for Dr Janet Sluggett. During the year the team expanded to include 21 members, including eight post-doctoral researchers, four statisticians/data managers, three research support, four PhD students and one Masters Student.

In 2022, the team received the first provision of linked data for the ROSA Prospective South Australian Cohort, which includes 26,600 older South Australians. In October 2022, the team delivered the inaugural ROSA Outcome Monitoring System Facility Reports on 12 quality and safety indicators to almost 90 eligible residential aged care facilities together with a public report for wide dissemination (<https://rosaresearch.org/rosa-oms>).



Australia & New Zealand Dialysis & Transplant Registry (ANZDATA)

ANZDATA researchers continue to engage in high-impact research activities by generating quality research evidence to inform healthcare decisions made by patients, health professionals, and policy makers. In 2021 ANZDATA researchers were successful in winning a number of grants to support this work. These projects address consumer priorities by embedding consumers as co-investigators.

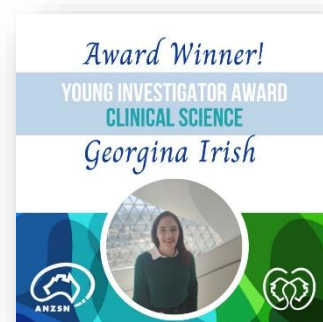
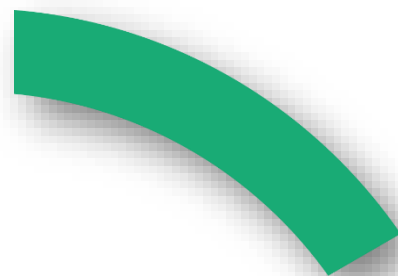
ANZDATA's Epidemiological Fellow Dr Georgina Irish was successful in winning the Young Investigator Award – Clinical Science through the Australian and New Zealand Society of Nephrology for her work in developing a clinical decision-making tool for clinicians and patients.

“For many people with kidney failure, a kidney transplant can greatly extend their lifespan. For some people though, transplantation can cause more harm than good compared to dialysis. Predicting which option is best for a given patient is an important and complex decision for both patients and clinicians, and an evidence-based approach can help to make an informed choice. Using the Australian New Zealand Dialysis and Transplant Registry (ANZDATA), researchers have developed flexible parametric models which provide this ‘absolute’ prediction of survival and allow for predictions many years into the future and prediction of quality-of-life benefit. This work will form the basis of a decision support tool, where patients and clinicians can enter the relevant patient details, and the application will provide the predicted results of each option”.

Georgina Irish MBBS, FRACP, MMed (ClinEpi)

Better Evidence and Translation – Chronic Kidney Disease (BEAT-CKD) initiated as a collaborative research network aiming to improve the lives of people living with chronic kidney disease. In 2021, BEAT-CKD researchers were awarded an NHMRC Centres of Research Excellence: Partnering with Patients with Chronic Kidney Disease to Transform Care and Outcomes, leveraging on the work already achieved.

Officially launching in November 2022, the CRE-PACT is a collaborative research program that aims to improve the lives of people living with chronic kidney disease in Australia and globally by generating high-quality research evidence to inform healthcare decisions made by patients, health professionals, and policy makers. ANZDATA plays a pivotal role within this diverse network and aims to collaborate alongside patients and caregivers across all stages of research in kidney disease.



Researchers at ANZDATA are conducting a qualitative study to explore the views and opinions of people with kidney disease, about quality indicator data of dialysis and transplant centres and ANZDATA's reporting of this information. With the aim to find out if this information is important to consumers to know, how it may impact their decision-making between kidney services and their experience of care and how ANZDATA reporting can improve for consumers and the public.



Discussions with participants include the benefits, potential risks and unintended impacts of public reporting of centre outcomes (such as transplant and dialysis patient survival rates) on patients. A related project is underway, involving surveying kidney clinicians' interpretation of various presentation formats of quality indicator data.

The National Indigenous Kidney Transplantation Taskforce (NIKTT) led by ANZDATA, established by the Commonwealth to improve access to, and outcomes of, kidney transplantation for Aboriginal and Torres Strait Islander Australians, has created an extensive national network of consumers, clinicians, researchers, and advocates. Projects funded by the NIKTT have found that: outreach assessment clinics to remote parts of Western Australia are exceptionally helpful in ensuring patients have access to workup and subsequent waitlisting; Aboriginal-led education sessions are useful to help both consumers and clinicians understand the unique complexity of transplantation for Aboriginal and Torres Strait Islander peoples with kidney failure; and Patient Navigator programs – where Aboriginal and Torres Strait Islander peoples with lived experience of kidney disease and transplantation help guide other patients through the complicated pathways to care and transplant – are highly valued and effective for patient groups around the country. An extension of this Patient Navigator work was awarded a \$1million MRFF grant this year, and is led by ANZDATA community engagement officer Kelli Owen, alongside an innovative model of Investigators that includes the Patient Navigators themselves working with nephrologists and nurses.

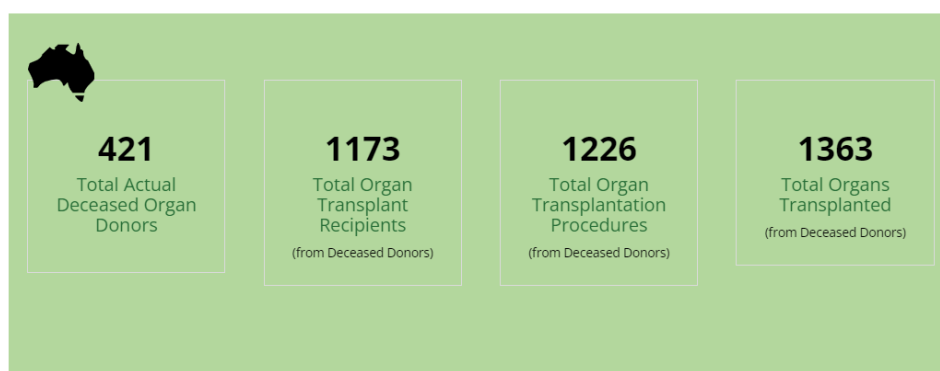
The ANZDATA embedded clinical trial Symptom Monitoring With Feedback Trial (SWIFT) aims to see if people who are managed with haemodialysis for kidney failure can benefit from more regular monitoring of their symptoms and if electronic feedback of these symptoms to their nurses and kidney doctors improves patients' overall wellness. The trial began in 2021 and has so far recruited 790 participants in NSW, QLD and SA, with VIC, TAS and WA commencing recruitment soon.

Australia & New Zealand Organ Donor Registry

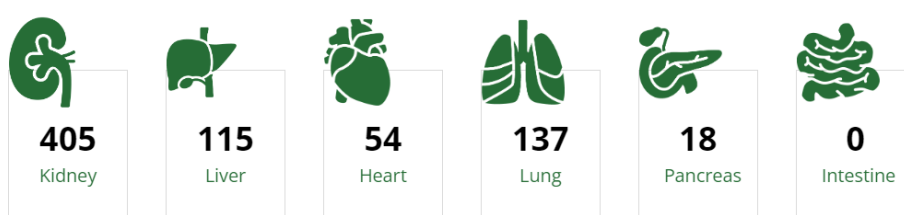
The Australia and New Zealand Organ Donation Registry (ANZOD) continues to collect and report on all organ, eye and tissue donation activity, that is used to produce a wide range of statistics for the local, national and international community. Work undertaken in 2022 supported the Australian Government Organ and Tissue Authority in the set-up of governance, oversight, and continual improvement for the OrganMatch system, a tool that assists clinicians in the treatment of patients waiting for transplant and for patients that have already received a transplant. As a key stakeholder ANZOD's collaboration focuses on continuing to enhance the needs of the Transplant and Organ donation sector. Research collaborations supported a significant piece of work to improve the current kidney allocation algorithm, with changes implemented in 2021 into OrganMatch that focused on improving access to highly sensitised patients, improved usage of donated kidneys and improving matching for younger patients,

ANZOD collaborations extended to the New Zealand Blood Service Donor Referral System solution with ANZOD providing key technical advice facilitating the development and improvements of the New Zealand counterpart to OrganMatch. This work promotes improved interoperability with existing clinical information systems and the potential for future linkage,

Latest Donation Activity - 2021 Data Release



Total Organs Transplanted



Australia & New Zealand Eye Tissue Donation Registry

Work in 2022 initiated a 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. This

project aims to continue the

reporting of donation and

transplantation activity through the use of efficiencies in data

transfer and significantly improve the flow of information for the

eye and tissue donation sector. Work supports monitoring and

reporting of the appropriateness and effectiveness of health

information particularly in eye donation.



Australia & New Zealand Living Kidney Registry

The Australia and New Zealand Live Kidney Donor (ANZLKD) Registry was established to provide information about the long-term health and well-being of people who donate a kidney for transplantation.

Data is submitted on all living kidney donation events monthly, by all Australian and New Zealand transplanting units and the Australian and New Zealand Paired Kidney Exchange Program (ANZKX).



Australian Particle Therapy Clinical Quality Registry (ASPIRE)

The Australian Bragg Centre for Proton Therapy and Research (ABCPTR) will be Australia’s first proton beam therapy (PBT) centre and the first of its kind in the Southern Hemisphere. Co-located with the Royal Adelaide Hospital, new Women’s and Children’s Hospital and South Australian Health and Medical Research Institute in the Adelaide BioMed City precinct, the ABCPTR provides additional treatment options to patients who require radiation therapy for solid tumours.

The ABCPTR building is due for practical completion by the end of 2023. There will be a further 12 -18 months of installation and commissioning of the PBT system before patient treatments commence. Ramp-up of services will occur over the first years of operation.

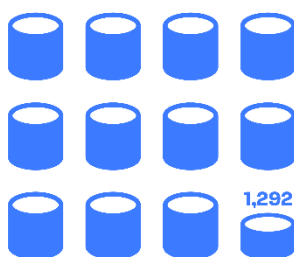
Seed funding was secured from the Hospital Research Foundation Group for the establishment of the Australian Particle Therapy Clinical Quality Registry (ASPIRE) in July 2021.

The funding agreement included provisions for registry staffing and the necessary ICT infrastructure to support the 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 these 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.



Registry Milestones

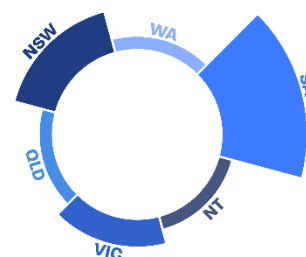


Completed fields

March 2023



Participants recruited



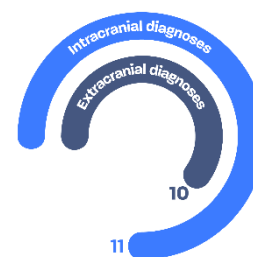
ASPIRE National Steering Committee representatives by jurisdiction

The ASPIRE protocol has been endorsed by the Trans-Tasman Radiation Oncology Group (TROG) Scientific Committee, registered with the Australian and New Zealand Clinical Trials Registry (ANZCTR):

ACTRN12622000026729p. The registry is also recognised and endorsed by the Australian Commission on Safety and Quality Health Care (the Commission).

The registry protocol and participant information sheet received ethical approval from the Women's and Children's Health Network (WCHN) Human Research Ethics Committee (HREC) under the National Mutual Agreement (NMA) scheme on February 2nd, 2022 - 2021/HRE00394. Followed by a site-specific agreement (SSA) which was approved for participant recruitment to commence in the Department of Radiation Oncology at the Royal Adelaide Hospital in March 2022.

The national rollout strategy for the registry is underway, with an SSA under review for the Alan Walker Cancer Care Centre in Darwin. The onboarding of additional national sites will be coordinated by the ASPIRE National Steering Committee in conjunction with the ASPIRE working group.



Diagnoses by type



1 site activated - RAH
1 site pending - AWCCC

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 (BreastSurgANZ), require members to submit data on all cases of early and locally advanced breast cancer. The BQA Subcommittee is responsible for providing direction, oversight and clinical advice to the operation of the audit. The committee has reviewed the current KPIs and data fields. These are in the process of being updated to better reflect more modern and up-to-date approaches to treatment and quality of care. The new look BQA will be released during the Royal Australasian College of Surgeons (RACS) Annual Scientific Congress in May 2023.

The format and content of the BQA annual report is under review, aiming for a new look. The last annual report published in 2019 examines data for breast cancers diagnosed in that year. Key results include:

- Most patients treated in 2019 were above 49 years of age and 99% were female.
- Patients with in-situ tumours or smaller invasive tumours were most likely to be referred from BreastScreen, while larger invasive tumours were more likely to be a symptomatic referral from a general practitioner (GP).
- Breast conserving surgery was the most common 'final' treatment for breast cancer, particularly for patients referred by BreastScreen, patients aged over 40, and for the treatment of smaller tumours.
- Patients aged 70 or above were the least likely to receive reconstruction after mastectomy.
- Most patients treated with breast conserving surgery received no further surgical treatment.

- Most invasive tumours were treated with some form of axillary surgery, commonly sentinel node biopsy. Axillary node dissection was more frequent as the tumour size increased.
- Patients with small in situ tumours were the least likely to have any axillary surgery. With larger tumours, the likelihood of sentinel node biopsy increased. Axillary node dissection was rare for in situ tumours
- Surgeons in Australia and New Zealand are meeting all six BQA KPIs.

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

The second report of the ANZELA-QI program was published in November 2022 and was presented as part of an Emergency Laparotomy Workshop hosted by the Victorian Preoperative Consultative Council (VPCC).

The key messages from the analysis of data collected between 1 January 2020 and 31 December 2021 were:

- Australia has a low mortality from emergency laparotomy compared to overseas reports
- The low mortality likely reflected the lessons learnt through the Australian and New Zealand Audit of Surgical Mortality relating to futile surgery
- When compared to the National Emergency Laparotomy Audit in England and Wales (NELA) compliance with evidence-based international care standards in Australia was poor and similar to those reported by NELA 10 years ago
- There was wide inter-hospital variation in both care and outcome
- There is little scope for individual clinicians to improve care; system and organisation changes are required
- When established in 2018, ANZELA-QI anticipated many of the recommendations of the second Australian Commission on Safety and Quality in Health Care Framework for Australian Clinical Quality Registries'.
In that regard:
 - ANZELA-QI has shown that reporting using near real time Statistical Process Control charts is feasible
 - the major barriers to progressing ANZELA-QI relate to governance approvals and securing long-term funding
- Recommendations from the VPCC suggest all hospitals: contribute to ANZELA-QI, perform routine preoperative risk assessment, to adopt the recommendations of the international guidelines for Emergency Laparotomy and the involvement of specialists in aged care medicine.





● **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 birth defects, including cerebral palsy. The Register collects information on all children born in South Australia on or after 1st January 1986 who have a significant birth defect detected in the first five years of life.

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

The SABDR has contributed non-identified data to The Australian Institute of Health and Welfare, as part of the recently re-established national congenital anomalies collection. This data was included in the first report the AIHW has released on congenital anomalies since 2008. Based on data from 6 jurisdictions across Australia, it presents information on congenital anomalies in babies born in 2016 that were diagnosed up to 12 months of age.

The SABDR contributed to a number of different research projects in 2022, including the provision of non-identified data as part of linkage projects.

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 2022, the latest annual SACPR report was published, presenting information for children with cerebral palsy born in the years 1993-2016. 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 1.38 per 1,000 live births (2014-2016).

The SACPR also contributed non-identified data to the Australian Cerebral Palsy Register. Established in 2008, the ACPR has grown to be the largest database of its kind in the world. The 2023 ACPR report is the 8th biennial publication published by members of the Australian Cerebral Palsy Register Group. This report demonstrated that the rate of cerebral palsy in Australia has fallen to 1.5/1,000 live births – the lowest in the world.

The SACPR contributed to a number of different research projects in 2022, including providing assistance with recruitment to studies, and providing non-identified data as part of linkage projects.

International Vitreoretinal B-cell Lymphoma Registry

When immune B-cells become cancerous this is called B-cell lymphoma, which mostly occurs in the body outside of the central nervous system (CNS) with good treatment outcomes. Rarely, it occurs inside CNS - which includes the brain, spine and the inside of the eyes. One or more of these sites may be affected at the same time, or at different times during the disease course. Inside the eye the lymphoma mainly affects the gel-like fluid, called the vitreous, and the cell layer at the back of the eye used for vision, called the retina. This is known as **vitreoretinal B-cell lymphoma**. It is a rare cancer affecting approximately 1 per 2 million people. The first symptoms of vitreoretinal lymphoma are common for some less rare eye conditions, and so diagnosis and treatment can be delayed.

Little is known about how lymphoma develops in the CNS and how it is best treated. When the brain is affected, survivorship outcomes are poor. However, recent studies indicate that when only the eyes are affected, early treatment might delay or even prevent the cancer eventually occurring in the brain, and so reduce the cancer burden and improve outcomes for the individual.

Because of its rarity, most of our understanding about vitreoretinal lymphoma comes from small clinical trials in high-income countries, and real-world data is lacking to help inform and develop best clinical practice. To this end, the **International Vitreoretinal Lymphoma Registry** project was recently established, based at Flinders University and in partnership with South Bank Medical Group, Brisbane. This investigator-led multinational initiative aims to provide real-world information about outcomes of management-focused practices for vitreoretinal lymphoma from across the globe. Anonymous clinical care data are lodged in the registry by ophthalmologists via a secure online platform.

Australian and New Zealand Audit of Surgical Mortality (ANZASM)

The Australian and New Zealand Audit of Surgical Mortality (ANZASM) facilitates the independent peer-review of all instances of patient in-hospital mortality where surgical care was involved. Starting as a pilot program at the University of Western Australia in 2001, with support from RACS and funding from local Departments of Health, the program has been rolled out across all Australian states and territories. Through the participation of all 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.

The ANZASM annual report for 2019–2020, containing data on audited cases from all states and territories except for NSW, is soon to be released. 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 the clinical management could have been improved, with delays to treatment 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.

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

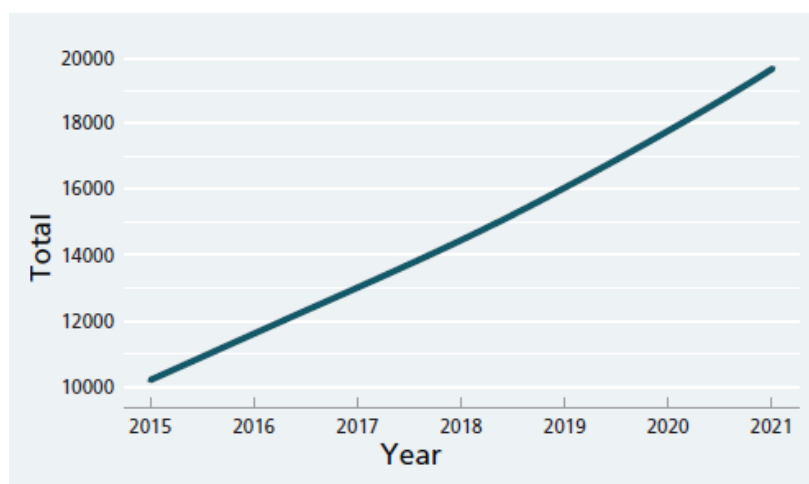
The South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC) registry was established in 1998.

The registry now holds data on more than 20,000 men with prostate cancer diagnosed in South Australia. Over recent years the registry has recruited over 90% of newly diagnosed cases in the state. It covers both public and private sectors.

The registry records demographic details about patients, together with their diagnostic procedures, pathology, biochemistry, treatment decisions and cause of death. The registry also collects patient reported outcome measures (PROMs) beginning before treatment commences, through to five years after treatment.

The registry provides quality indicator reports to participating clinicians and health service providers which benchmark individual performance against peers

Database Growth



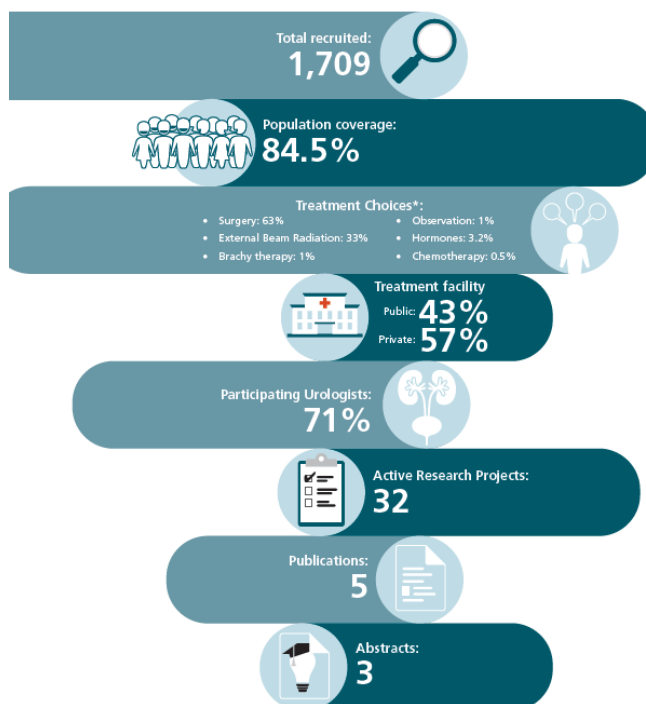
SA-PCCOC database - growth 2015-2021

across Australia and New Zealand. These reports are generated by the national registry (Prostate Cancer Outcomes Registry of Australia and New Zealand – PCOR-ANZ) using deidentified data.

The registry data also supports a research programme with projects undertaken by clinicians, academics and students at honours masters and PhD levels.

The registry activities are supported by generous funding from the Movember Foundation, The Hospital Research Foundation, the Urological Society of Australia and New Zealand (SA-NT section) and Mundi Pharma.

2021 SA-PCCOC Snapshot



* Assignments such as Observation take time to clarify and allocate, and are likely to grow.

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 8653 individuals over the past 15 years. The recruitment is ongoing with an additional 397 individuals for 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. 227 specialists from across Australia and New Zealand have referred participants to ANZRAG. The most prevalent participants were Advanced Glaucoma (35%), followed by Non-Advanced Open-Angle Glaucoma (24%).

Participants from every state and territory, including New Zealand, United States, Canada and the United Arab Emirates have been recruited and provided a DNA sample in 2022: 9 from the Australian Capital Territory, 1 from the Northern Territory, 26 from New South Wales, 35 from Victoria, 9 from Western Australia, 3 from Tasmania, 16 from Queensland, 282 from South Australia, 5 from the United States, 4 from the United Arab Emirates, 6 from New Zealand and 1 from Canada.

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 five publications this past year.

Exome data analysis led to the discovery of a novel candidate gene for Primary Congenital Glaucoma in collaboration with Prof JL Wiggs (Harvard Medical School, USA).

We have also recently reported that a high Polygenic Risk Score (PRS) was associated with younger age at first glaucoma surgery and more rapid progression in early disease.

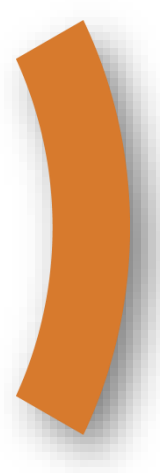
Selected advanced and non-advanced glaucoma cases from the ANZRAG study have also formed the cohort for the TARRGET study which will inform first-degree relatives of their risk of developing glaucoma.

Australian Corneal Graft Registry (ACGR)

The Australian Corneal Graft Registry had another successful year in 2022, with over 2,000 registration forms received - an annual record for the Registry. The database now contains over 44,000 registered corneal transplants in almost 30,000 individual graft recipients. Almost 12,500 (28%) grafts continue to be followed. An annual request for follow-up was sent to surgeons in September. Almost 6,000 grafts had updated follow-up information provided during 2022, with 130 grafts now followed for more than 30 years.

The major achievement for the Registry in 2022 was the publication of our latest major report in May. This 378-page document (which is freely available online at: <https://doi.org/10.25957/9vyp-0j93>), provides in-depth analyses of the outcomes of grafts registered in the ACGR database since its inception in 1985. Analyses are provided for different types of grafts, with further comparisons made across graft types for common indications for graft. Observations on the impact of the COVID-19 pandemic on the practice of corneal transplantation in Australia in 2020 are also detailed. Interruptions to elective surgery, under which corneal transplantation predominantly falls, were experienced across many jurisdictions.

A review article was published in the Journal of Clinical and Experimental Ophthalmology, titled “Outcomes of corneal transplantation in Australia, in an era of lamellar keratoplasty”. In November, the ACGR was invited to give a presentation as part of a registry-focused session at the Royal Australian and New Zealand College of Ophthalmologists Congress in Brisbane. We highlighted the importance and usefulness of the ACGR in providing individual audits to surgeons and eye banks, a service which continued to be regularly requested and delivered throughout 2022.





● **PRODUCT REGISTRIES**

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

Transcatheter Aortic Valve Implantation (TAVI)

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.

A review of the Registry in late 2021 saw the implementation of suggestions in 2022. The significant highlights included:

- a change in the internal management structure of the TAVI-R at SAHMRI,
- introduction of SAHMRI biostatistical support resulting in an extensive improvement in the analysis and reporting of TAVI data and the ability for the registry to fulfil ad-hoc data requests,
- discussions initiated on the potential expansion of the TAVI-R to include additional procedures,
- finalising preparations for a site source data audit in 2023,
- significant improvements to data cleaning practices to reduce site burden, and
- review of the current data collection form for scheduled release early 2023

In addition, 2022 saw the TAVI-R

- submit an application for the Registry to be published on the searchable table of clinical registries on the Australian Commission on Safety and Quality in Health Care website,
- represented on the SAHMRI Centre Advisory Committee,
- continued involvement in the ACOR TAVI Steering Committee and Working Group
- commencement of an additional 6 data contributing sites bringing the national total to 48 sites, and
- data collection reaching close to 13,500 TAVI cases.

Dental Implant Registry (DIR)

The Dental Implant Registry took some more great strides in 2022. We set up an educational arm in the Academy for Implant Mastery (AIM Education), which was very well received in its first year, with several courses being run and many happy attendees gaining a variety of new skills, techniques and better understandings of dental implantology.

The registry itself experienced another uptake in both new users to the software and in registration numbers for the year. Our team attended and exhibited at some trade shows and conferences to network with more dental specialists, manufacturers and suppliers.

Our application saw more leaps forward in accessibility and functionality, allowing more users to easily utilise and incorporate into their practices and workflows. We are looking forward to another few major changes being rolled out in early 2023 as well.

The DIR team we fortunate enough to be part of the SAHMRI Steering Committee and learn from the incredible minds and trailblazers that work with the various other registries within SAHMRI. This has helped us move the DIR in the right direction, with goals of changing from a product registry to also begin research projects that will help the dental implant industry for the better.







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