THE BENCHMARK

A quarterly publication of the partnership between Monash University, the SAHMRI Registry Centre and the Australian Clinical Trials Alliance.







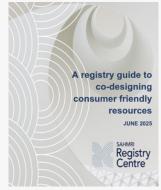
From the Editorial Team: **Professor Susannah Ahern, Samuel Golding, Cheryl Grant** (Monash University), and **Natalie Shalit** (ACTA), we are pleased to welcome you to Edition 9 of *The Benchmark*. We hope you enjoy the new look of the Newsletter.

REGISTRY NEWS

EXPANSION OF NATIONAL CQR PROGRAM BEST PRACTICE MATERIALS AND RESOURCES

Following the completion of the SAHMRI Consumer-Friendly Resources and Expanding Best Practice in Registry Science projects (covering public reporting, advisory services, value and impact, and data linkage), a suite of best practice materials and resources is now available on the **National CQR Program website**.

These resources were developed from the funding provided by the Australian Government, Department of Health, Disability and Ageing, under the National Clinical Quality Registry Program. Thank you to the SAHMRI Registry Centre Executive Group, Advisory Group, Registry Centre members and CQR sector for your involvement and support. For further details or feedback contact registrycentre@sahmri.com



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TAVI IS TRANSITIONING TO ATVT

Building on the success of the Transcatheter Aortic Valve Implantation Registry (TAVI-R), Australasian Cardiac Outcomes Registry (ACOR) and South Australian Health and Medical Research Institute (SAHMRI) have launched the **Australian Transcatheter Valve Therapies Registry** (ATVT-R).

This comprehensive registry is designed to collect procedural and device-related data across all four cardiac valves (aortic, mitral, pulmonary, and tricuspid) in order to monitor the safety and performance. As of 24/9/2025, 23 existing TAVI sites have migrated their aortic valve procedures to the ATVT Registry database, of which 15 sites are now also collecting mitral and tricuspid procedures. We anticipate the migration of all 54 TAVI Registry sites to the ATVT Registry database by November 2025.





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EMERGENCY LAPAROTOMY CLINICAL CARE STANDARD - CONSULTATION DRAFT

The Emergency Laparotomy Clinical Care Standard consultation draft contains nine quality statements and a set of indicators to support the key aspects of care relating to the processes and outcomes for people undergoing emergency laparotomy in Australia. Each quality statement is explained for consumers, clinicians, and healthcare services. Consultation is now open for the draft from Wednesday 10 September and will close on

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Tuesday 14 October 2025.

THE AUSTRALASIAN LEUKAEMIA AND LYMPHOMA GROUP (ALLG) NATIONAL BLOOD CANCER REGISTRY (NBCR) EXPANDS TO CAPTURE CHRONIC LEUKAEMIA DATA

The ALLG NBCR is moving into a new chapter in 2026 by expanding to capture data in both **Chronic Myeloid Leukaemia (CML)** and **Chronic Lymphocytic Leukaemia (CLL)**. The inclusion of the chronic leukaemias into this well-established national blood cancer registry will provide opportunities to both strengthen research and advance clinical insights in this space, whilst also serving as a screening and eligibility pathway for the ALLG clinical trials program. Haematologist Dr Courtney Tate (Princess Alexandra Hospital, ALLG NBCR CML Steering Group Chair) says 'Including chronic leukaemias in the NBCR gives us the data we need to understand real-world treatment patterns, identify gaps in care, and improve outcomes for people living with CML and CLL'.



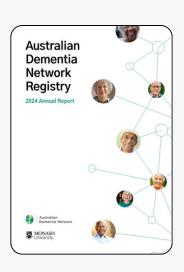
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ADNET REGISTRY ANNUAL REPORT 2024

The Australian Dementia Network (ADNeT) Registry released its 2024 Annual Report during the Dementia Action Week and shared its latest achievements in a public webinar to an audience of clinicians, researchers, policy makers, and people living with dementia and their families. The ADNeT Registry is a crucial data asset for monitoring the quality of diagnosis and care for people with mild cognitive impairment and dementia in Australia, thereby driving improvements in patient outcomes. The 2024 Annual Report demonstrates how clinicians around Australia are accessing best practice data to develop and refine their care for Australians living with dementia.





NATIONAL CLINICAL QUALITY REGISTRY (CQR) PROGRAM - CQR EXPANSION CAPACITY BUILDING GRANTS - G07883

The purpose of this grant opportunity is to increase national coverage of CQRs in line with Strategy Pillar 2: Priority 7. High national coverage is essential for generating reliable insights and driving nation-wide improvements in clinical practice and patient outcomes.

This grant opportunity is aimed at:

- · Existing national CQRs looking to achieve full capture of their in-scope population, and
- Existing state-based or local registries looking to expand into a national CQR (noting for the
 purposes of this grant opportunity, national expansion must achieve registry participation in
 a minimum of two additional states and/or territories).

 FURTHER INFORMATION



UPCOMING EVENTS

ACTA 2025 Clinical Registries Symposium

REGISTER NOW for the <u>ACTA 2025 Clinical Registries Symposium</u>, 18-19 November at the Crown Promenade, Melbourne where this year's theme *Driving Change*, highlights the influence of clinical registries in shaping better healthcare and outcomes for patients.

PROGRAM

Whether you're building a registry, enhancing data quality, or translating insights into policy and practice, this event offers hands-on workshops, cutting-edge presentations, and invaluable networking with national and international experts.

REGISTER HERE



REGISTER HERE

SHORT COURSE - PROMS

Patient-Reported Outcome Measures (PROMS) for Clinical Registries - 25 February 2026

This practical course has been designed for clinicians, researchers, registry coordinators and other healthcare professionals planning to or currently collecting PROMs, and will be based on a conceptual framework model and guidelines for the use of PROMs in clinical registries. Early bird discount for registrations received before 30 November 2025.

MRDR ANNUAL BREAKFAST MEETING

The **Myeloma and Related Diseases Registry** is pleased to host the MRDR Annual Breakfast Meeting at Blood/ISBT 2025 in Perth on 27th October, 7:50-8:15 am (AWST). This hybrid event is a great opportunity to hear updates on the latest registry data and progress and current MRDR projects. Click Read More for further information and registration details



LYMPHOMA BREAKFAST MEETING

The hybrid **Lymphoma Breakfast Meeting** is co-hosted by the Australasian Lymphoma Alliance (ALA), Lymphoma and Related Diseases Registry (LaRDR) and Lymphoma Australia (LA) on Tuesday, 28 Oct 2025 7:00-8:30 am (AWST). The theme for the meeting is "Working together to improve lymphoma patient outcomes". We will present updates on the work of the ALA, LaRDR, and LA.



REGISTER HERE

IMPACT STORY

ANZDATA/ANZSN SPECIAL REPORT: KIDNEY CARE UNDER PRESSURE – MANY UNITS STRUGGLE TO DELIVER TIMELY DIALYSIS ACROSS AUSTRALIA AND NEW ZEALAND

ANZDATA in conjunction with the Australian and New Zealand Society of Nephrology (ANZSN) have released their Special Report: Unit Survey 2024, examining workforce variability and haemodialysis service constraints across Australia and Aotearoa New Zealand. Key findings highlight staffing pressures, limited dialysis capacity, and adaptive strategies to support patient care.



Article links regarding the publication: The Limbic, and SAHMRI

Link to report, infographic and commentary:

READ MORE

REGISTRY HIGHLIGHTS

MRFF GRANT AWARDED TO DEVELOP A BI-NATIONAL EATING DISORDERS REGISTRY, ONE OF THE FIRST OF ITS KIND IN MENTAL HEALTH

Researchers across five universities and led by University of Technology Sydney have been awarded a \$2 million grant (2025-2029) to further develop and expand the Australia & New Zealand CQR for Eating Disorders (know more broadly as the TrEAT Registry). The four year grant will also be used to show the value of the expanded registry through two research streams that include (1) an embedded evaluation of the eating disorder specific Medicare items in private outpatient practice, and (2) the development of clinical prediction models that will support clinicians to select the treatment approach that is most likely to result in good outcomes based on their clients' individual characteristics. The research involves input from diverse end-users of the registry including people with eating disorders, carers, clinicians, researchers, and policy workers. To learn more about the registry and associated research, readers can visit the website or contact Deb directly (deborah.mitchison@uts.edu.au).



TEAM OF THE YEAR

We are delighted to announce that the **Australian Stroke Clinical Registry (AuSCR)** has been awarded the Florey Team of the Year. This recognition celebrates the team's collaborative achievements, and innovative work in transforming stroke care across Australia. With major grant success, expanded hospital participation, powerful new data tools, and a bold vision for the future, they have pioneered improvements that will benefit patients and services nationwide.

LtoR: Nancy Pompeani, Peter Van Wijngaarden, Dominique Cadilhac, Julie Morrison, Kate Paice, Pamela Butt, Mya Thander



OUALIFIED PRIVILEGE

The Australasian Registry of ECGs in National Athletes (ARENA) has now received a declaration of qualified privilege under the Health Insurance Act 1973. This will provide important protection for participating clinicians and sporting organisations. ARENA is a long-term international data repository of athlete cardiac screening which aims to improve our understanding of ECG interpretation, cardiac diagnoses, and the rates of major cardiovascular outcomes in screened athletes.



WANTED!

PART-TIME DATABASE MANAGER

ANZVASC-QDR Database Manager and Registry Development

The ANZ Vasculitis Quality and Disease Registry is a new registry with 8 active sites and 8 more sites completing governance. The ANZVASC-QDR is looking to employ a 0.4 FTE manager/developer. Please contact Professor Richard Kitching (<u>richard.kitching@monash.edu</u>) if you are interested and for further information.





ANZICS CORE INFORMATICS LEAD

12 month contract with ANZICS ICU Registry. Lead the ongoing development of the IT Infrastructure to support the strategic goals for ANZICS Clinical Quality Registries.



NEW MEMBERS WELCOME

The **ACTA Clinical Quality Registries (CQR) Special Interest Group** is now welcoming new members. By joining, you'll become part of a vibrant community of practice dedicated to strengthening and advancing CQRs across Australia. As a member, you'll gain access to regular webinars featuring influential speakers from the Australian Government – including those shaping national policy – alongside leading subject matter experts.



REGISTER HERE

PUBLICATIONS

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