

# 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, Cheryl Grant** (Monash University), and **Natalie Shalit** (ACTA), we are pleased to welcome you to Edition 11 of *The Benchmark*.

## EVENT NEWS

### SAHMRI REGISTRY CENTRE DATATHON 2026

On 12 March 2026, the **South Australian Health and Medical Research Institute (SAHMRI)** hosted its second Registry Centre **Datathon**, bringing together clinicians, data scientists, and researchers to collaboratively tackle pressing clinical questions using large datasets. Participants formed teams to analyse data from sources such as the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), the Australia and New Zealand Intensive Care Society Registry (ANZICS) and the Australia and New Zealand Hip Fracture Registry (ANZHFR), aiming to derive meaningful insights within a limited timeframe.

The winning team: **'The Homeward Care Collective'** analysed data from the ANZICS Adult Patient Dataset to determine *'Who makes it home after ICU admission in Older Australians?'*



### SAHMRI REGISTRY CENTRE ANNUAL SYMPOSIUM 2026

The Registry Centre held its **2026 Annual Scientific Symposium** on 13 March 2026 once again a sell-out event, attracting more than 135 attendees.

This year's theme, "Advancing Equity through Clinical Quality Registries", was strongly shaped by insights from keynote and plenary speakers:

- Professor Michael Kidd AO – Chief Medical Officer for Australia
- Assoc Professor Courtney Ryder – Co-Director, FHMRI Health Equity Impact Program, Flinders University
- Mary Ann Bauero Geronimo – CEO, Federation of Ethnic Communities' Councils of Australia

Key focus areas included leveraging registry data to identify and better understand inequities; addressing ethics, governance and data sovereignty; strengthening reporting approaches; and driving quality improvement and policy impact.

The Symposium concluded with a powerful and engaging session highlighting meaningful consumer and community involvement in registry design, governance and implementation.

[SYMPOSIUM RECORDINGS](#)



## AUSTRALIA AND NEW ZEALAND LIVING KIDNEY DONOR (ANZLKD) REGISTRY ANNUAL REPORT

The 1<sup>st</sup> **Australia and New Zealand Living Kidney Donor (ANZLKD) Registry Annual Report** is now published on the **ANZORRG (Australia and New Zealand's Organ Replacement Therapies Registry Group)** website.

This report describes the trends and characteristics in living kidney donation in Australia and New Zealand. The data for this chapter come from the ANZLKD Registry. Much more information about living kidney donors in Australia and New Zealand can be found on the **ANZLKD website**.

The ANZLKD registry has been in operation since 2004, but this material has previously been published in the ANZDATA annual report. This report will develop in coming years under the guidance of the Living Kidney Donation working group.

Thanks to those involved in the LKD data intake and those who contributed to the preparation of the report.



## AUSTRALIAN BREAST DEVICE REGISTRY (ABDR) 2024 ANNUAL REPORT

The **Australian Breast Device Registry (ABDR) 2024 Annual Report** presents registry data from 242 sites and 449 clinicians, comprising 9,765 patients, 18,842 procedures and 11,902 devices in 2024. Trends and outcomes are reported separately for cosmetic and reconstructive procedures. For the first time, revision proportions attributable to clinical complications versus patient preference are presented.

[VIEW THE FULL REPORT](#)



## AUSTRALIAN CYSTIC FIBROSIS DATA REGISTRY (ACFDR) 2024 ANNUAL REPORT

The **Australian Cystic Fibrosis Data Registry (ACFDR)** has recently published its **2024 Annual Report**. This report features diagnostic, clinical outcome and management data from 3,788 people with **Cystic Fibrosis (CF)** across Australia, alongside national benchmarking data for the 24 Australian CF centres. Expanding upon previous editions, the 2024 report presents many complications and treatment data over time, highlighting trends in pulmonary therapies, CF-related disease and multidisciplinary care. The 2024 data showcases ongoing improvements in lung function and survival, and highlights key areas for ongoing management such as persistent respiratory infections and diabetes.

[VIEW THE FULL REPORT](#)



# NATIONAL CARDIAC REGISTRY (NCR) ANNUAL STATUS REPORT 2025

The **National Cardiac Registry (NCR)** collects information regarding **Percutaneous Coronary Intervention (PCI)**, a procedure to widen or unblock arteries to restore blood flow to the heart.

The **NCR Annual Status Report 2025** is a comprehensive summary of PCI activity in Australia, including performance and outcome data on procedures from January to December 2024. The report includes year-on-year trends, analysis and benchmarking which can be utilised for continuous quality improvement measures in cardiovascular care.

[VIEW THE FULL REPORT](#)



## SAHMRI REGISTRY CENTRE 2025 ANNUAL REPORT

The **fourth Annual Report** of the **SAHMRI Registry Centre** highlights 2025 as a year of growth, transition, and major achievements. The Centre continued to strengthen its national profile, expand its collaborative network, and welcome three new registries. Key milestones included significant staff transitions, including the retirement of Cindy Turner, completion of Australian Government-funded Centre of Excellence and Consumer-Friendly Information (CoFI) projects, and the release of new national guidance resources in September 2025 through the **National Clinical Quality Registry Program**. The report also showcases the 27 member registries, highlighting their 2025 activities and key achievements

[VIEW THE FULL REPORT](#)



## UPCOMING EVENT

In February 2027, **Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)** will mark a significant milestone: 50 years since the Registry was established in 1977.

To recognise this milestone, we will be hosting the **ANZDATA 50th Anniversary Datathon and Symposium**, held 17–19 February 2027.

This event will bring together ANZDATA's community to reflect on the journey so far, celebrate shared achievement, and focus on what comes next, including the next generation of kidney research and researchers.

*Please save the date in your diary!*



[FOR MORE INFORMATION](#)

## RUNNING FOR REGISTRIES

The **Neonatal Alloimmune Thrombocytopenia (NAIT) Registry** extend their appreciation to the Augusto family and the **'Run for Rui'** team. Having lost their son, Rui, to NAIT, a rare but devastating condition caused by the mother's antibodies targeting fetal platelets, Marcio and Sarah Augusto chose to turn their grief into action. Working with Sleepy's Foundation, a charity which supports fundraising for those affected by illness, and H events, a family-run sport event organiser, they initiated the hugely successful 'Run for Rui' fundraiser. The fundraising goal was more than doubled, impressively showing the impact community and consumer engagement can have for registries.



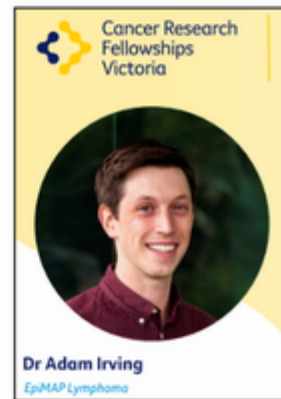
Left to right: Ms Tasmyn Greentree, Mr Neil Waters, Mrs Helen Haysom, Dr Karina Brady, Professor Zoe McQuilten, Ms Nikki Byrnes, Mrs Robynn Sleep, Mrs Sarah Augusto, Mr Marcio Augusto, Professor Erica Woods, Ms Claire Smales

## REGISTRY HIGHLIGHTS

### EPIDEMIOLOGICAL MODELLING OF AUSTRALIAN PATIENTS WITH LYMPHOMA (EPIMAP LYMPHOMA)

The **Lymphoma and Related Diseases Registry (LaRDR)** data will be central to the national health-economics modelling project to map trends and treatment outcomes of Australian patients with lymphoma. This work will be led by **Dr Adam Irving**, a health economist and the 2025 Cancer Research Fellowship Victoria recipient.

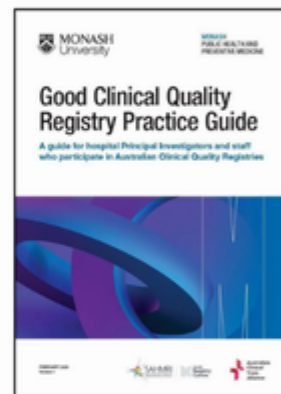
[LEARN MORE HERE](#)



### GOOD CLINICAL QUALITY REGISTRY PRACTICE GUIDE

The **Good Clinical Quality Registry Practice Guide** provides best practice training for hospital staff and clinicians as they begin participating in national Clinical Quality Registries.

[CLICK HERE TO VIEW THE GUIDE](#)



### GOOD CLINICAL QUALITY REGISTRY PRACTICE TRAINING MODULE

The **Good Clinical Quality Registry Practice Training Module** is a free course based on the Guide which provides essential knowledge needed to participate safely and effectively in Clinical Quality Registry activities, supporting high-quality healthcare through real-world data collection and analysis.



Good Clinical Quality Registry Practice

1 Feb 2026 (Enrolments Close: 31 Jan 2027)

Self-paced

Free

[CLICK HERE TO ENROL IN THE TRAINING MODULE](#)

## OVER 10,000 PATIENTS ENROLLED IN LYMPHOMA AND RELATED DISEASES REGISTRY (LARDR)

The **Lymphoma and Related Diseases Registry (LaRDR)** has reached a significant milestone, with over **10,000** lymphoma patients enrolled as of March 2026. This registry, supported by hospitals and research partners across Australia and New Zealand, plays a vital role in collecting real-world data to inform clinical practice and improve patient outcomes.

LEARN MORE  
HERE

## PHD CONFERRED

In February 2026, Nashwa Najib's PhD was conferred by the University of New South Wales, Sydney. Her PhD thesis, titled '*Decoding the Natural History of Degenerative Cervical Myelopathy: A Longitudinal Registry-based Study Integrating Proteomic Profiling and Health Data Linkage*' is now published on UNSWorks.

READ HERE

Under the supervision of Prof Ashish D Diwan, Dr Najib's PhD focused on addressing the research priorities as outlined by AO Spine RECODE-DCM.

## TrEAT REGISTRY DEVELOPMENT

The **TrEAT Registry** is one of the first mental health registries in our region. It is now under a major period of development with the support of an MRFF Research Data Infrastructure Grant (2025-2029). One of the first milestones of this grant was to publish the CQR's protocol, which is now available in the open access, field-leader, Journal of Eating Disorders. To learn more about the CQR, access the [protocol](#), or visit the [website](#).



## OTHER

### AUSTRALIAN GOVERNMENT UPDATE

The implementation of the National Clinical Quality Registry Program is in progress. To receive updates on funding opportunities, register on [AusTender](#) and [Grant Connect](#), and check the Department's [website](#) for previous outcomes. The website also offers [CQR best practice guides](#) and an interactive map of participating sites.



Australian Government  
Department of Health, Disability and Ageing

## PUBLICATIONS

Douglas TA, Pourghaderi AR, Ahern S, Corda J, Earnest A, Mulrennan S, Ranganathan S, Ruseckaite R, Shanthikumar S. The impact of telehealth on clinical outcomes in adults and children with cystic fibrosis in Australia. *J Cyst Fibros* 2025; 29: S1569-1993(25)02548-2 [doi: 10.1016/j.jcf.2025.12.017](#)

Jayasinghe RT, Ahern S, Maharaj AD, Romero L, Ruseckaite R. Implementing patient-reported outcome measures: A scoping review of existing guidance across clinical trials, practice and registries. *Public Health* 2026; 252: 106138 [doi: 10.1016/j.puhe.2026.106138](#)

Mitchison D, Basten C, Bennett K, Bray M, Byrne S, Goldstein M, Hay PJ, Heruc G, McGill K, Prnjak K, Roberts ME, Rogers K, Russell P, Taggart N, Tame J. The Australia and New Zealand clinical quality registry for the treatment of eating disorders (TrEAT Registry): protocol and preliminary data. *J Eat Disord* 2025; 14: 31 [doi: 10.1186/s40337-025-01506-5](#)

Wickremasinghe AC, Garduce P, Brown DL, Budin AJ, Chadwick C, Leang YJ, Talbot M, Ahern S, MacCormick AD, Caterson ID, Brown WA. Incidence and indications for revisional metabolic bariatric surgery: A 10-year analysis from the Australian and New Zealand Registry. *Ann Surg* 2026; [doi: 10.1097/SLA.0000000000007013](#)

Have feedback or content for the next edition?  
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