

# The Benchmark

Contact Us  
[acta@acta.au](mailto:acta@acta.au)

*The Benchmark is a quarterly publication of the CQR Collaboration Hub. The newsletter is circulated to members of the ACTA Clinical Quality Registry Special Interest Group (ACTA CQR SIG), and is also published on the ACTA website.*

## FROM THE EDITORIAL TEAM

**Professor Susannah Ahern (Monash University)**



**Natalie Shalit (ACTA)**

**Cheryl Grant (Monash University)**

Welcome to the **eighth** edition of The Benchmark.

Introducing the **new ACTA Clinical Quality Registries (CQR) SIG Leadership Team** - Welcome to the **new co-chairs**:

**TAMARA HOOPER** is the Senior Project Manager, SAHMRI Registry Centre. Tamara is an experienced project manager who has led and managed many complex research projects, including the Registry-Nested Clinical Trials portfolio whilst at the AOANJRR, established the ACOR TAVI Registry, and has held commercial healthcare roles nationally within the education, marketing and sales environment. Tamara is passionate about growing the CQR sector in the same way that there is recognition for clinical trials, research and education in the health service environment. Her goal is for the CQR sector is to reduce variation through standardisation, working collaboratively, reducing waste (duplicate effort) and demonstrating the value and impact of registries.



**JADE NEWMAN** is the Clinical Registries Data Manager for IVF registries within the NPESU at UNSW Sydney. Jade brings a wealth of experience and a deep commitment to advancing registry science. Her professional background is in biostatistics, clinical trials, project and registry management and she is currently pursuing a professional doctorate in Applied Public Health, with an emphasis on impact evaluation. Jade was interested in the CQR co-chair role because it is a unique opportunity to leverage the collective expertise of the SIG in a creative and strategic manner, to support the needs of the CQR sector, and ensure it remains at the forefront of registry science.



Also, a warm welcome to our **brand-new Executive Committee members**:

- **Helena Kopunic** - Program Manager, Surgical Audit at Royal Australasian College of Surgeons (RACS)
- **Jocasta Ball** - Director of Research Strategy and Senior Research Fellow in the Centre of Cardiovascular Research and Education in Therapeutics at Monash University
- **Kelly Skelton** - Registry Project Manager at the Australian Bragg Centre for Proton Therapy and Research, leading the ASPIRE Registry
- **Ken Sleeman** - Consultant Anaesthetist and Director, DayCOR Registry
- **Michael O'Callaghan** - Clinical Epidemiologist at Flinders Medical Centre and Executive Officer, South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC)

We look forward to working together to support and enhance a community of practice for CQRs in Australia.

And a **HUGE thank you** to our outgoing co-chairs **Stephen McDonald** and **Susannah Ahern** for your leadership and expertise over the years.

# Farewell

After more than 10 years working in the CQR sector, I would like to share that I will be retiring from my role as the **Strategic Director of the SAHMRI Registry Centre**, effective mid-July. It has been a privilege to work alongside such talented colleagues and to contribute to the growth and success of the Registry Centre and to work with many of you across Australia.



I'm pleased to announce that Tamara Hooper will be stepping into the role of Strategic Director. Tamara brings a wealth of experience in health, research, clinical trials and registries, and I have every confidence that she will continue to drive our work forward with skill and dedication. Please join me in welcoming Tamara to the role and thank you all for the opportunity to work with you over the years.

I look forward to keeping up to date (from afar) of the developments of clinical quality registries within Australia and seeing the impact and the enormous value of the work you all do to continue to grow the sector.

Keep up the good work

Kind regards

**Cindy Turner**

## CQR Impact Story

### Empowering IVF patients

The **Australian and New Zealand Assisted Reproduction Database (ANZARD)** is the world's oldest and most comprehensive IVF clinical quality registry that monitors the safety and quality of IVF treatment in Australia and New Zealand. All fertility clinics provide data to ANZARD on the IVF cycles they perform and is the only source of national data to inform consumers, the medical community and governments about IVF treatments performed in Australia and New Zealand. A lack of transparency for consumers about IVF success rates led the Australian Government to fund the development of the YourIVFSuccess website. It contains two consumer tools which use data supplied by fertility clinics as part of their submission to ANZARD:

A Patient Estimator where users can calculate their individual chances of having a baby using IVF treatment. This calculator uses interpretable machine learning algorithms on data from over 800,000 IVF cycles in ANZARD.

A searchable database of all accredited IVF clinics in Australia, including their success rates.

The website won the 2023 Research Australia Award for Data Innovation in recognition of its value to consumers and receives over 4,000 visitors each month. Lucy and Zoe are two patients who have kindly shared their stories and the role of YourIVFSuccess in their journeys.

[Read Lucy's story](#)



Lucy's IVF Journey

From uncertainty to joy with the help of YourIVFSuccess



Zoe's IVF Journey

Finding confidence with YourIVFSuccess

[Read Zoe's story](#)



**MONASH**  
University



# Update from the Australian Department of Health, Disability and Aged Care

The **National Clinical Quality Registry Program** is underway. If you wish to be notified of new funding opportunities, please register your interest on [AusTender](#) and [Grant Connect](#) and regularly check the Department's [website](#), here you can also find outcomes of previous opportunities. Also note we have a group mailbox that you can also send these requests to: [cqrpolicy@health.gov.au](mailto:cqrpolicy@health.gov.au).

## PHRN CROSS-LINK project

- Main contact: Felicity Flack [felicity.flack@uwa.edu.au](mailto:felicity.flack@uwa.edu.au)
- CROSS-Link project. This project is a national collaboration to establish a framework for streamlined, efficient and routine linkage of CQRs (and supports Pillar 6 of the National Strategy).  
Project Aims and Work programs:
  - a. Understand consumer and community attributes to routine linkage (Work program = Consumer and community involvement) (Monash leading lead – Belinda Gabbe)
  - b. Develop a streamlined governance framework (Work program = Governance) (PHRN leading)
  - c. Develop and test a new digital solution for routine linkage of multiple registries (Work program = Efficient linkage) (AIHW leading)

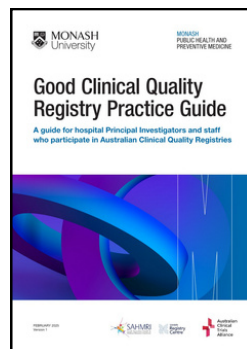
## National Clinical Quality Registry Program

New best practice guides are now available on the **National CQR Program** website

<https://www.health.gov.au/resources/collections/national-clinical-quality-registry-program-best-practice-materials>

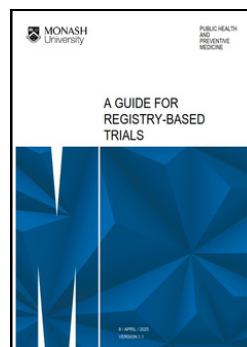
### The **Good CQR Practice Guide**:

The Good CQR Practice Guide has been developed by CQRs with input from the Commission. It supports clinicians and site PIs who are participating in CQRs for the first time by providing high level information on CQRs that can be complemented by registry-specific training.



### **Guide for Registry Based Trials**:

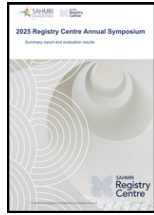
The Guide for Registry Based Trials has been developed with CQR operators and researchers. It provides information on how to conduct registry-based trials and offers practical tools and examples to support implementation.



# Strategic Activity

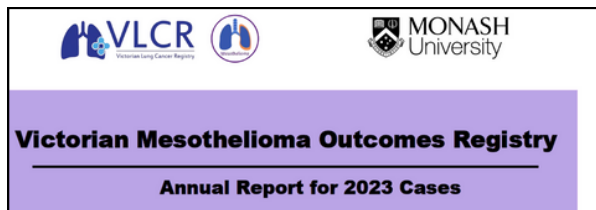


[2024 SAHMRI Registry Centre Annual Report](#) released in March 2025 is now available online. The report provides readers with the Registry Centre aims, governance, a summary of registry centre activities and member achievements for 2024.



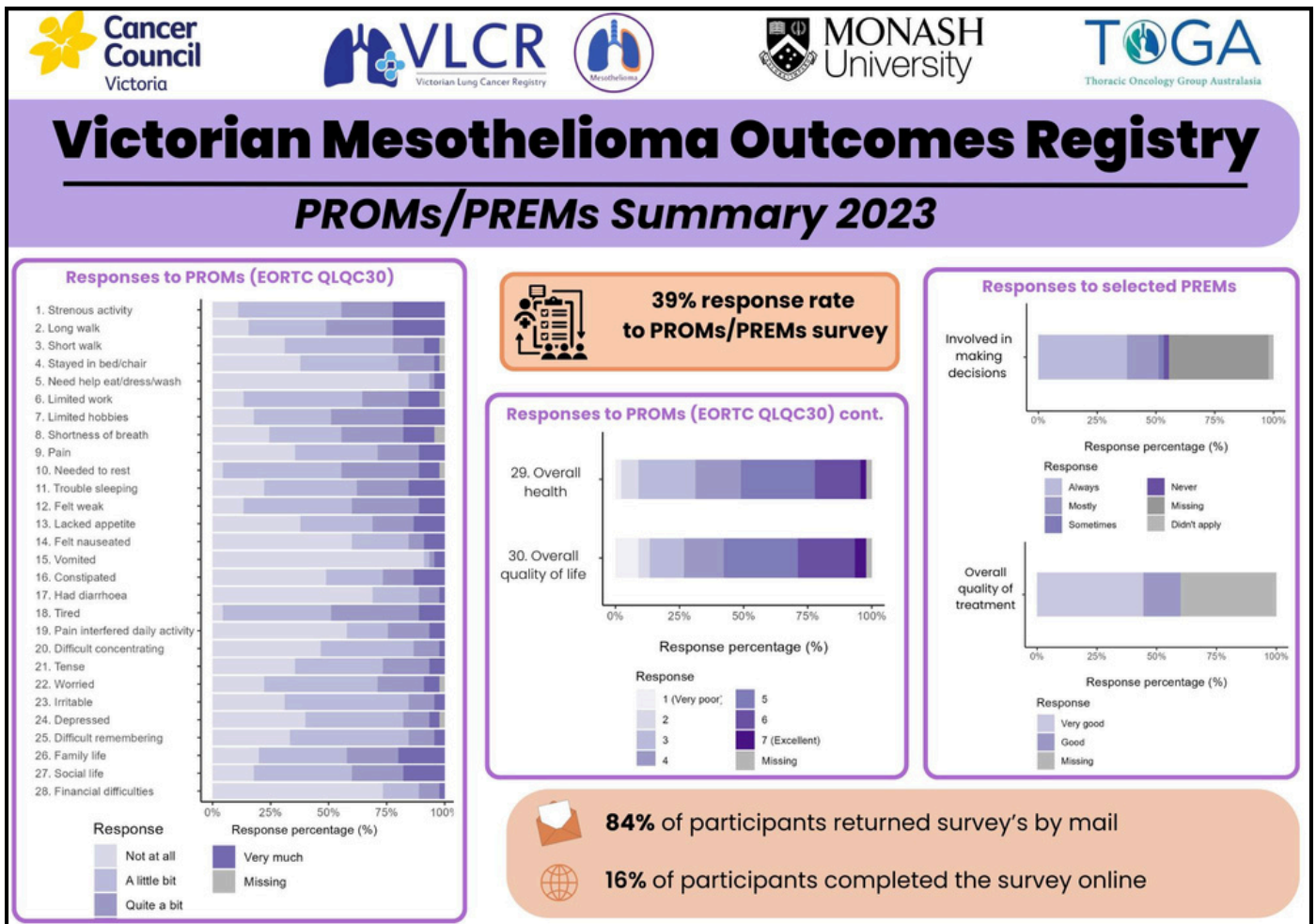
[2025 SAHMRI Symposium Report](#) - The Symposium has been become an important event on the CQR Sector calendar and in 2024 the Symposium became a recognised CQR Collaboration Hub event. In 2025, it was a sellout event with a 16% increase in attendees compared with 2024. Preceding the Symposium the SAHMRI Registry Centre hosted its Inaugural Datathon in collaboration with the Australia and New Zealand Intensive Care Society (ANZICS) Registry, the Australian & New Zealand Dialysis and Renal Transplant Registry (ANZDATA) and the Registry of Senior Australians (ROSA). The report provides a summary of both events and results from the evaluation.

The **Victorian Mesothelioma Outcomes Registry (VMOR)** was established in 2022 to collect data on all newly diagnosed mesothelioma patients in Victoria.



The registry recently released its 2023 Annual Report, which features the first analysis of Patient-Reported Outcome Measures and Patient-Reported Experience Measures. Through this work, VMOR aims to highlight the experiences of people living with mesothelioma across Victoria and to identify and address potential disparities in access to care and support services.

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## Milestones

The **Lymphoma and Related Diseases Registry (LaRDR)** has reached a significant milestone, with over **9,000** lymphoma patients enrolled as of 8 May 2025. 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.

The **Australian Particle Therapy Clinical Quality Registry (ASPIRE)** had two stories published last week – one by SAHMRI, and the other by CAHLN with Nurses week:

<https://sahmri.org.au/news/research/300-and-counting-rah-hits-milestone-for-landmark-cancer-registry-at-sahmri>

[300 and counting: Royal Adelaide Hospital leads landmark cancer therapy study](#)

In April 2025, the **Dental Implant Registry (DIR)** launched its first webinar, [From Register to Registry](#). The event brought together leader's in implant dentistry for engaging and forward-thinking discussions, chaired by Emeritus Professor Alastair Goss. It marked a significant milestone for the DIR, highlighting how data can drive better outcomes for patients while improving systems and processes across the entire dental implant supply chain.

## Registry Publication

Baldwin HJ, De La Mata N, Sara G, McMillan F, Biles B, Wu J, Lawton P, McDonald S, Webster AC. Closing the gap in kidney disease: validating the reporting of Aboriginal and/or Torres Strait Islander identification in a clinical quality registry using linked data. *Medical Journal of Australia* 2025; 222: 240-248. Doi: 10.5694/mja2.52613

### Summary of the work:

New research shows we underestimated the number of Indigenous people with kidney failure in NSW by approximately one-third. If we want to make headway closing the health gap for Aboriginal and/or Torres Strait Islanders, we need better health data to plan and measure change.

Indigenous people get more kidney disease, get fewer kidney transplants, and die younger than other Australians. ANZDATA is the clinical registry used to record treatment and outcomes for kidney failure in ANZ; it underpins national policy initiatives including the National Indigenous Kidney Transplant Taskforce. But 1/3<sup>rd</sup> Aboriginal people in NSW are invisible in health statistics. This suggests not all clinical services are asking patients the national standard question “are you of Aboriginal or Torres Strait Islander origin?” and assuming them not Indigenous. Or are people choosing not to self-identify for fear of negative impact, due to structural racism in healthcare?

The 1/3<sup>rd</sup> Aboriginal people in NSW who were not recognised in ANZDATA were different from those that were. They were more likely to live in cities, be male, be younger or older, but most importantly they had better health - they got more kidney transplants and lived longer. Looking at other single data sources we see similar under-identification of Indigenous people, so ANZDATA is not alone in this. NSW Health routinely uses their “Enhanced Reporting of Aboriginality” algorithm that looks across multiple health data sources for any individual to ascertain if Aboriginal status is recorded. What this research shows us is that integrating multiple data sources improves accuracy and we should not rely on single sources. The message is that accurate data matters, and that integrating data from other sources is an important mechanism for quality assurance.

[Professor Angela Webster FAHMS](#)