

The Benchmark

Contact Us
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 (the CQR SIG), and is also published on the ACTA website.

FROM THE EDITORIAL TEAM

Professor Susannah Ahern (Monash University)



Professor Stephen McDonald (SAHMRI)



Cindy Turner (SAHMRI)



Welcome to the **fifth** edition of the Benchmark. The Registry SIG has grown to represent **90 registries** and **140 individual members**, and these figures continue to grow! In December 2023 the Hub identified **125 clinical registries**: our aim is to grow the membership to sign up every single one. We encourage members to invite other registries and registry colleagues to sign up. To do this, please have them email acta@acta.au.

Our newsletter this month features a spotlight on the **Victorian Cardiac Outcomes Registry (VCOR)**. ACTA's next **CQR SIG meeting** is on 9th October from 12-1pm and will focus on opportunities for collaboration between CQRs and Clinical Trial Networks. Speakers include Cecilia Ng, Chair, Special Interest Group for Clinical Trial Network Managers (SIGNet) and Jo Fitzsimons, Executive Officer of the Australian Early Psychosis Collaborative Consortium, with an introduction and CQR update by Susannah Ahern.

Save the date - December 2-4, Melbourne. We are delighted to announce that this year we have teamed up with our colleagues at ACTA to deliver a joint ACTA and Registry Annual Scientific Meeting. The Organising Committee were delighted at the numbers of abstracts and workshop proposals received, a program will be available shortly.

Registry Spotlight

The **Victorian Cardiac Outcomes Registry (VCOR)** is a Clinical Quality Registry established in 2012 to monitor the outcomes of cardiac procedures in Victoria.

Percutaneous coronary intervention (PCI), an interventional procedure used to treat blockages in the coronary arteries and the first VCOR module. Data are currently collected from all 34 PCI hospitals in Victoria and three in Tasmania. VCOR benchmarks these hospitals quarterly against key indicators, including door-to-balloon times, in-hospital major bleeding, 30-day risk-adjusted mortality, and unplanned cardiac readmissions. The registry also includes a Cardiac Implantable Electronic Device (CIED) module, with 14 hospitals contributing data.

With data on over 115,000 procedures, the registry has been pivotal in monitoring and reporting trends in the care provided to PCI patients over the past 10 years. In 2020, VCOR collaborated with the National Cardiac Registry (NCR) to provide a national perspective. Registry data has also been used by researchers, resulting in over 65 peer-reviewed publications.



The 2023 VCOR Annual Report was published in August 2024 and is available at <https://www.monash.edu/medicine/sphpm/vcor/publications>.



MONASH
University



SAHMRI
South Australian Health &
Medical Research Institute



Australian
Clinical
Trials
Alliance



DEVELOPMENT OF THE GOOD CQR TRAINING GUIDE

The **Good CQR Training Guide** is an alternative, more pertinent resource for registries to the Good Clinical Practice training for clinical trials. The Guide will feature Forewords from the Department of Health and Aged Care, and the Australian Commission on Safety and Quality in Health Care, and is currently being designed for publication. Following completion of the Guide, work on an online training module will commence. We would like to thank all who took part and provided their time to complete this important guide.

Australian Government Update

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](#).

Australian Commission on Safety and Quality in Health Care Update

New resource - Australian Framework for National Clinical Quality Registries 2024

In August 2024, the [Australian Framework for National Clinical Quality Registries 2024](#) was published by the Australian Commission on Safety and Quality in Health Care (the Commission), marking a significant update to the original edition from 2014. The Framework supports CQRs in collecting, analysing, and reporting clinical data, to maximise the value of Australia's clinical data. It aligns with the Australian Government's National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030, ultimately leading to better patient outcomes across Australia.

What's new about the Framework:

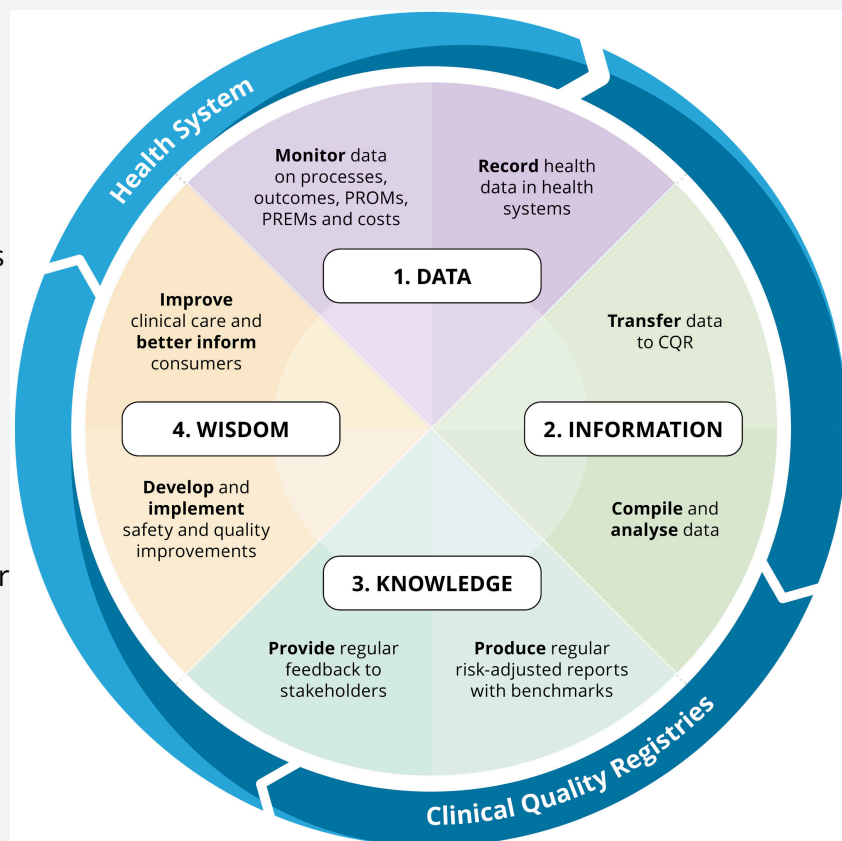
- Emphasises the role CQRs play in driving improvements across the health system
- Quality Standard for CQRs
- Self-assessment checklists

First released in 2014, the Commission developed the Framework to provide best-practice guidance for establishing and operating CQRs. Over 120 clinical registries are now listed on the [Australian Register of Clinical Registries](#).

The Commission would like to thank our partners who have guided the development of the revised Framework and implementation resources.

Please visit the Commission web site at

<https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/national-guidance-clinical-quality-registries> or email CQR@safetyandquality.gov.au for any further information.



Registry Milestones

- The **Australian Orthopaedic Association National Joint Replacement Registry 2024 Annual Report** marks a major milestone—the 25th edition of AOANJRR's comprehensive review of hip, knee, and shoulder arthroplasty. Focusing on prostheses still in use, this year's report uncovers fresh insights trends. Revision rates for 2023 hit record lows, with hip replacements at 7.1%, knee replacements at 6.8%, and shoulder replacements at 6.9%, the lowest yet reported. A special feature on practice variation highlights intriguing differences in hip and knee surgeries across Australia, from surgeon practices to prosthesis choices. Despite regional variations, overall trends show improved outcomes and increased use of advanced surgical techniques. Explore the full report and 14 supplementary reports, **available from October 1, 2024**, including deeper dives into specific topics. Stay informed with the latest data shaping the future of joint surgery! <https://aoanjrr.sahmri.com/annual-reports-2024>
- The **Australian Diabetes Clinical Quality Registry (ADCQR)** is the first clinical quality registry established in Australia for adults with diabetes. The ADCQR's first year of implementation was completed in 2023 capturing health and patient reported outcomes from 1426 patients across 25 diabetes health services (sites) in Australia. The activity is currently in progress for the 2024 data collection with an impressive 49 sites contributing data to the Registry. The ADCQR successfully launched their **2023 Annual Pooled Report** during National Diabetes Week in July 2024 to inform and promote the activity amongst diabetes health services. The Launch webinar is now available for viewing on the ADCQR website. Please click on the following link: [Resources - Australian Diabetes Clinical Quality Registry \(ADCQR\) \(monash.edu\)](https://www.monash.edu/adcqr/resources)
- The **Lymphoma and Related Diseases Registry (LaDR)** has captured data from **8,000 lymphoma patients** as of 23 July 2024
- The **Australian Breast Device Registry (ABDR)** has reached a significant milestone, with over **100,000 registrants** (patients) recruited since the pilot program began in 2012. As a CQR, the ABDR actively monitors trends and complications relating to breast device procedures, and tracks the long-term safety and performance of implantable breast devices (including breast implants, tissue expanders and mesh/matrix products). Operating under an opt-out consent model, the registry has consistently reported high participation rates throughout its 12-year history. Among the small number (approximately 1%) of patients who chose to opt-out, the most frequently cited reasons were lack of interest and removal of their breast device. Importantly, patients retain the option to opt-out of the registry at any time. The ABDR would like to express its gratitude for the ongoing support and engagement by consumers, as their participation is crucial in advancing the registry's mission of improving breast device safety and contributing to evidence-based clinical practice.
- **Australian and New Zealand Hip Fracture Registry (ANZHFR) 2024 Annual Report** now available. In 2023, 100 ANZ hospitals contributed more than 17,700 hip fracture records to make this report possible. It is an opportunity to celebrate progress and reflect on areas that remain challenging. Hans (aged 98) offers unique insight into his experience of hip fracture care – and we highlight our steps in strengthening relationships with consumers, as we strive to ensure they are our partners in improvement efforts. The Clinical Care Standard Report and Supplementary E-Report can be downloaded at <https://anzhfr.org/registry-reports/>. And if you only have a few minutes, check out our **video highlighting key results** (<https://www.youtube.com/watch?v=yKXa7q4VaBI>). The ANZHFR thanks clinical teams, health services and partner organisations for their ongoing commitment to improving care and outcomes for older people after hip fracture.
- The **Australian Dementia Network (ADNeT) Registry** released its **2023 Annual Report** at a public webinar attended by people living with dementia and their families, clinicians, researchers, and policy makers. The registry captures data from a diverse group of Australians newly diagnosed with dementia or mild cognitive impairment (MCI), including those from regional and remote settings, and culturally and linguistically diverse backgrounds. Managed by Monash University, the ADNeT Registry provides data-driven insights that inform clinical practice, shape policy, and support research to improve access to high-quality care. The ADNeT Registry 2023 Annual Report can be downloaded from <https://www.australiandementianetwork.org.au/initiatives/clinical-quality-registry/#anchor-3>.
- The **Victorian Lung Cancer Registry (VLCR)** has recently released their **2022 Annual Report** (<https://vlcr.org.au/index.php/researchreports/>)



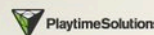
Registry Publication

The **Lymphoma and Related Diseases Registry** (LaRDR) has published a manuscript on the Australian experience with ibrutinib in patients with relapsed/refractory mantle cell lymphoma: *Baggio D et al. Australian experience with ibrutinib in patients with relapsed/refractory mantle cell lymphoma: a study from the Lymphoma and Related Diseases Registry. Leukemia & Lymphoma. (<https://doi.org/10.1080/10428194.2022.2157676>)*

Registry Grant Funding

The **Australian Stroke Clinical Registry** (AuSCR) was recently successful in securing funding via the Australian Government's National Clinical Quality Registry Program ([National Clinical Quality Registry Program | Australian Government Department of Health and Aged Care](#)). The funding will assist in expanding the registry to more hospitals throughout Australia, include alternative participation models for small hospitals to monitor stroke care, allow additional data dashboards to be created and support hospitals in working to achieve National Stroke Targets. More information from The Florey's media release can be found [here](#).

ANZICS in partnership with **QUT**, and **Playtime Solutions** secure \$1.5 Million in Australian Government Funding to Enhance ICU Care through the **ICU Forecast Project**



Events



ANZ REDCap User Day 2024 28 October 2024

ANZ REDCAP USER DAY 2024

Monash University is hosting the community-led **ANZ REDCap User Day**.

DATE: 28 October 2024 - 10:00 AM - 05:00 PM

LOCATION: 553 St Kilda Road, Melbourne VIC 3004

Program details: <https://redcap.link/anzredcapagenda2024>

Register: <https://redcap.link/anzredcap2024>

Available online or onsite.

ACTA 2024 Clinical Trials and Registries Symposium

The **ACTA 2024 Clinical Trials and Registries Symposium** will take place in **Melbourne** between **2-4 December** at the Pullman Melbourne Albert Park Hotel. Registrations are now open: <https://acta2024.com.au/acta-registration>



EXPANDING BEST PRACTICE IN REGISTRY SCIENCE

Project #2 Piloting a National CQR Advisory Service

This is a national service currently being piloted by the SAHMRI Registry Centre. Registries are encouraged to contact or refer others to the Centre.

The CQR Advisory Service is able to provide advice and support in the following areas:

- General enquiries from individuals or organisations considering establishing a CQR, assistance to determine if a CQR is an appropriate response.
- Advice and tools to assist establishment of a new CQR
- Advice and support regarding further development of existing registries seeking to move their registry closer to meeting the requirements of the Australian Framework for National CQRs
- Advice and guidance for CQRs seeking to undertake more advanced activities such as registry nested trials, data linkage studies, international collaborations and comparisons, strategic planning, audit review.

For enquiries please contact the SAHMRI Registry Centre at registrycentre@sahmri.com

Project #3 Increasing CQR value and impact case studies and analysis

Registry relevance: Demonstrating impact is becoming increasingly important for registries i.e. funding, research, ensuring registry relevance, funder & other stakeholder requirements.

The SAHMRI Registry Centre recently hosted a half day workshop for 25 of its members titled “Fundamentals of IMPACT for Registries”. The workshop was facilitated by Tamika Heiden, Principal and Founder of Research Impact Academy (RIA). Participant feedback indicated this workshop delivered practical learnings and tips for Registries to implement. The SAHMRI Registry Centre are exploring other opportunities to repeat the workshop more broadly.

For enquiries please contact Tamara Hooper at registrycentre@sahmri.com

Guideline for PROMs reporting from CQRs to healthcare providers

Developing resources to help CQRs, clinicians and other providers to better analyse, interpret and utilise patient reported outcomes (PRO) data forms part of Strategy Pillar 1: Priority 4. Reporting of PROs to health services for quality improvement is a relatively new activity for many CQRs and health care providers. Via an approach that included a literature review, interviews and focus groups, Monash University has developed a Guideline on how CQR PRO programs can be established, implemented, analysed, and presented to providers, for maximum clinical care impact. The Guideline will be available later in 2024.

Best practice clinical reporting for impact

Providing data back to sites and clinicians is a defining feature of a CQR and forms part of Strategy Pillar 2: Priority 9 and Priority 18. However, there has been little research regarding how CQR reports to providers can be informed by existing audit and feedback evidence. Via a scoping review, survey, and interviews with CQRs, Monash University has developed a set of recommendations aligned to current best practice audit and feedback evidence. This includes recognition of many existing CQR processes that are evidence-based, as well as opportunities, for improvement for CQRs. The project report will be available later in 2024.

Upcoming Short Courses

Professor Arul Earnest:

Join me in this on-line short course on 21 Oct 2024 to explore the power of Bayesian techniques for analyzing data from clinical registries, routinely collected health data & cohort studies. The course will cover Bayesian theory, hands-on experience with WinBUGS software, and practical applications to spatially referenced health data. No prior experience in Bayesian statistics is needed. For further information on the course and registration, please see:

<https://www.monash.edu/medicine/sphpm/study/professional-education/introduction-to-bayesian-analysis>

Dr Ahmad Reza Pourghaderi:

Automating Interactive Reporting Using R

Unlock the power of R for automated, interactive reporting with our two-day online workshop, tailored for both beginners and experienced professionals, happening on 25-26 November, 2024. This workshop will guide you through the fundamentals of R programming, data manipulation, and visualisation on Day 1, ideal for those new to R or looking to refresh their skills. Day 2 focuses on advanced reporting techniques, using R Markdown and Shiny to create dynamic, sophisticated reports and interactive dashboards for participants with prior R experience. Designed for data analysts, professionals, and researchers, this online workshop provides a unique opportunity to enhance your reporting capabilities. Join us via Zoom and elevate your reporting skills—register now on our course [webpage](#) or via the QR code



Seeking Consumer Representatives

The **Australian and New Zealand Hip Fracture Registry (ANZHFR)** is seeking Consumer Representatives

The purpose of the Australian and New Zealand Hip Fracture Registry (ANZHFR) is to improve the hospital care and recovery for older people who break their hip.

What is the role of the consumer in the ANZHFR?

The ANZHFR offers a variety of opportunities, including:

- Providing input on ANZHFR resources or activities
- Advising on what matters to older people after hip fracture
- Sharing their story at the annual ANZHFR conference

Will consumers be paid for participating?

Consumers receive \$50/hour (including GST) plus travel costs

Who should apply?

The ANZHFR values input from people who have experienced a hip fracture as a patient or carer, but welcomes enquiry from anyone passionate about improving health care for older people.

How to find out more

Scan the QR code or contact Narelle Payne, ANZHFR Consumer Engagement Lead, via email myhipmyvoice@anzhfr.org or on (02) 9399 1072.

