

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 (ACTA 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 **seventh** edition of The Benchmark. We welcome new members of the ACTA Clinical Quality Registry SIG, now at 148 individuals as of March 2025. **We encourage new CQR members to sign up.** To do this, please **email acta@acta.au** with a brief outline of your current role and workplace.

Welcome to **Jade Newman**, the new ACTA Registry SIG Co-Chair. Jade is the Data Manager for the Australia and New Zealand Assisted Reproduction Database (ANZARD). Jade is based at the Centre for Big Data Research in Health at the University of New South Wales.

ACTA is calling for nominations for a second co-chair to join Jade in leading the SIG.

The ACTA Clinical Trials and Registries Symposium is planned for 17-19 November 2025, and members of the ACTA Clinical Quality Registry SiG are invited to nominate for the Registry Organising Committee. Please contact ACTA (bernie.withers@acta.au) before 4 April 2025 if you are interested.

Registry Spotlight



The **Australian Cystic Fibrosis Data Registry (ACFDR)** is a Clinical Quality Registry that commenced in 1996 and is managed by Monash University's School of Public Health and Preventive Medicine in collaboration with Cystic Fibrosis Australia (CFA) as shared data custodians. TSANZ, the Thoracic Society of Australia and New Zealand have endorsed the registry which aims to improve the health and quality of care given to patients with cystic fibrosis (pwCF). ACFDR is funded by the Commonwealth Department of Health and Aged Care, and CFA with funding support from industry.

The registry collects data related to the diagnosis, care and management of pwCF from public hospitals across Australia that treat the disease. Nearly 3,800 pwCF are currently enrolled in the registry .

The ACFDR recently published its **25th Annual Report**:

The ACFDR is in the process of developing a new registry module for collecting Patient Reported Outcome Measures (PROMs) from children and adults with CF. These PROMs will provide an efficient way to support clinical care for CF and assist pwCF transition safely from regular clinical encounters to a less frequent model of clinical interaction.



Additionally, the ACFDR will conduct a study to assess and compare pregnancy and early childhood outcomes in women on ETI (Evacaftor/Tezacaftor/Ivacaftor). ETI is the newest cystic fibrosis transmembrane conductance regulator (CFTR) modulator drug approved for the treatment of pwCF. The ACFDR database module will be developed to include additional data fields on medication exposures during pregnancy, pregnancy outcomes and complications, and developmental outcomes in infants and children.

SAHMRI Registry Centre Datathon

On March 19, 2025, the South Australian Health and Medical Research Institute (SAHMRI) hosted its inaugural **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) and the Australia and New Zealand Intensive Care Society (ANZICS) Registry, aiming to derive meaningful insights within a limited timeframe.



Datathon Mentors taking it all very seriously



Datathon Teams hard at work

The winning team: **'Shi(f)t happens: Statistically speaking'** addressed: ICU Staffing resources question and mortality outcomes (e.g. Clinical nurse educator full-time equivalents and mortality outcome), consultant to admission ratio, or other clinical endpoints such as length of stay. Their findings, presented at the end of the day, provided valuable insights and highlighted areas for further investigation.



SAHMRI Registry Centre Annual Symposium 2025

The South Australian Health and Medical Research Institute (SAHMRI) hosted its 2025 Registry Centre Annual Symposium on March 20, 2025. This year's theme, "**Advancing Healthcare through Registry Data and Analytical Insights**," explored how advanced registry analytics can transform data into actionable insights. Notable speakers included Professor Anne Duggan, CEO of the Australian Commission on Safety and Quality in Health Care, and Professor Ginny Barbour, Editor-in-Chief of the Medical Journal of Australia.

A highlight of the Symposium was the much-anticipated **'Grater Debate'**, where the panel tackled the pressing issue of increasing registry participation. Expertly moderated by Dr. Gillian Caughey, the debate featured insightful contributions from Dr. James Aitken, Dr. Michael O'Callaghan, Dr. Georgina Irish and Dr Gerry O'Callaghan. The discussion explored key questions, including whether incentives (the carrot) or penalties (the stick) are more effective in driving participation, how much data collection is truly necessary, and where the responsibility lies for ensuring engagement. The panel also debated the bold proposition of mandating registry participation across the board. With sharp insights, lively exchanges, and thought-provoking perspectives, the 'Grater Debate' sparked meaningful dialogue among attendees, highlighting both the challenges and opportunities in strengthening clinical registry involvement.

The **Good Clinical Quality Registry (CQR) Practice Guide** supports PIs and hospital staff participating in CQRs. The Guide fills a gap by offering practical, introductory guidance (similar to GCP training for clinical trials) on what CQRs are, why they matter, and how hospital teams can safely and effectively engage in registry activities.

The Guide was developed with input from many Australian CQRs and the Commission, via the ACTA Clinical Quality Registry SIG, and was funded by the Commonwealth Department of Health. The final hard-copy guide has been completed and will soon be available on the Department of Health's website.

A **Good CQR Practice training module** is being developed from the Guide to bring the content to life through real-world scenarios, interactive elements, and knowledge checks. Designed to be completed in ~45 minutes, users who successfully complete the final assessment will receive a certificate as formal recognition of their learning.

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](#), 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.

Registry Publications

- Brown WA, Brown DL, Holland JF, Campbell A, Cottrell J, Ahern S, Reilly J, Garduce P, Wetter J, Hamdorf JM, Talbot M, Baker S, MacCormick AD, Caterson ID. Metabolic bariatric surgery generates substantial, sustained weight loss and health improvement in a real-world setting. *ANZ J Surg* 2025. doi: 10.1111/ans.19378
- Tracy LM, Capell E, Cleland HJ, Edgar DW, Singer Y, Teague WJ, Gabbe BJ. Feasibility of collecting long-term patient-reported outcome data in burns patients using a centralised approach. *Burns* 2025; 51: 107304. doi: 10.1016/j.burns.2024.107304
- Vrolijk JJ, Becherer BE, Garduce P, Pourghaderi AR, Young-Afat DA, ven der Hulst RRJW, Farrell G, Walker M, Tansley P, Mureau MAM, Earnest A, Ahern S, Rakhorst HA. Comparing international revision incidence of commonly used breast implants. *JAMA Surg* 2025; e246933. doi: 10.1001/jamasurg.2024.6933
- Wang L, Chung E, Wellard C, Barraclough A, Campbell BA, Chong G, Di Ciaccio PR, Gregory GP, Hapgood G, Johnston AM, Tam CS, Opat S, Wood EM, McQuilten Z, Hawkes EA. Definitions and use of tumour bulk in phase 3 lymphoma trials: a comprehensive literature review. *Blood Adv* 2025. doi: 10.1182/bloodadvances.2024015072
- Wong EY, Wellard C, Ng JY, Chung E, McQuilten ZK, Opat S, Wood EM, Talaulikar D. Real-world data on lymphoma in Adolescents and Young Adults (AYA) - Report from the Lymphoma and Related Diseases Registry (LaRDR). *EJHaem* 2025; 6: e1096. doi: 10.1002/jha2.1096



SAHMRI REGISTRY CENTRE INVITES YOU TO Seminar #1 2025

CQRs within the AIHW National Health Data Hub

**What is the AIHW National Health Data Hub?
Do CQRs fit and what preliminary work is being done in this sector?
Perspective(s) from the exemplar project**

9th April 2025

12:30pm – 2:00pm ACST

- in-person SAHMRI, North Terrace Adelaide (rm 08.209)
- online [Teams link](#)

SPEAKERS

- Miriam Lum On
 - Head, Integration Development Unit, Data Governance & Integration Group, AIHW
- Shaila Chavan (ANZICS)
- Dominique Cadilhac (AuSCR)

More information registrycentre@sahmri.com

SAHMRI Registry Centre

Clinical Quality Registry ADVISORY SERVICE

Unlock Expert Support for Your Clinical Quality Registry with Our Advisory Service

Our experienced advisors are ready to assist you, whether you're just starting out or looking to undertake more advanced activities.

Achieve Your Registry Potential With:

- Tailored, expert advice to:
 - Establish a new registry
 - Expand an existing registry
 - Advance activities
- Comprehensive tools & templates
- Support via phone, email, or video
- Ongoing follow-ups



CONTACT US!

registrycentre@sahmri.com

[SAHMRI Registry Centre Website](#)



**MONASH
University**



SAHMRI
South Australian Health &
Medical Research Institute



**Australian
Clinical
Trials
Alliance**

Past Event

In March, the ACTA STInG hosted a webinar with **Dr Swarna Vishwanath** presenting on “**Developing a Best Practice Guide for Registry Based Trials**” (RBTs). RBTs leverage existing clinical registries to offer faster, cost-effective alternatives, enhancing Australia's research capacity. However, they face methodological and operational challenges. The webinar detailed a project focused on creating a best practice guide to support the planning, execution, and documentation of RBTs. The guide's development was informed by a scoping review, a national multi-stakeholder expert meeting, and semi-structured key informant interviews. Findings highlighted key enablers and challenges to the design and conduct of RBTs in Australia. Developed by the School of Public Health and Preventive Medicine at Monash University, with funding from the Australian Government Department of Health and Aged Care under the National Clinical Quality Registry Program, the guide offers key considerations for trialists and registry operators. The guide is now publicly available and can be accessed at

<https://www.monash.edu/medicine/sphpm/registries/registry-based-research/developing-a-best-practice-guide-for-registry-based-trials>. A recording of the webinar is available on the ACTA website <https://clinicaltrialsalliance.org.au/resource/acta-webinar-developing-a-best-practice-guide-for-registry-based-trials/>

Upcoming Events

 Royal Australasian College of Surgeons
Australian and New Zealand Audit of Surgical Mortality

Learning from Clinical Quality Registries

An ANZASM webinar hosted by WAASM

Monday, 7 April 2025

6:00pm AWST

Online via Microsoft Teams

Register to receive link to view online



Registration link is: [Register for WAASM webinar here](#)

[ACTA 2025 Trial of the Year Awards – ACTA – Australian Clinical Trials Alliance](#)

[ACTA Webinar – Data Integrity Tool for assessing the integrity of randomised trials – ACTA – Australian Clinical Trials Alliance](#)



MONASH
University



SAHMRI
South Australian Health &
Medical Research Institute



**Australian
Clinical
Trials
Alliance**

Milestone

In February 2025, the **Australian Stroke Clinical Registry (AuSCR)** reached the milestone of 200,000 episodes of care recorded in the registry. The AuSCR team acknowledged this milestone with representatives from consortium partners Stroke Foundation and Monash University, as well as Northern Health, who entered the 200,000th episode. We recognise and appreciate all the hard work from all hospital contributors to enter this data and efforts in using insights from the registry to improve the quality of acute stroke care at your hospitals.



The AuSCR team with Stroke Foundation and Monash University Representatives

Expression of Interest

Registry expert for Australian Stroke Clinical Registry Operational and Quality Improvement Committee

The **Australian Stroke Clinical Registry** is currently restructuring its governance and replacing the current Management Committee with an Operational and Quality Improvement Committee. We are seeking an external registry expert to sit on this Committee. The Committee will provide day-to-day oversight of the AuSCR and provide direction and advice on registry activities. The Committee will meet up to six times per year, generally via videoconference. If you would be interested, please email Program Manager, Julie Morrison julie.morrison@florey.edu.au for further information.

ACTA CQR SIG Executive Committee

The Executive Committee is responsible for shaping the direction of the group through leading and supporting group initiatives and its associated events. If you are interested in being a member of the executive committee for the ACTA CQR SIG, please briefly outline where you work, your professional background or qualifications, current role and why you're interested in being on the committee. This will help us ensure that we have a wide range of perspectives, ideas, and diversity.

Submissions to be sent to: natalie.shalit@acta.au. Deadline for submissions: April 14th.

ACTA CQR SIG Co-Chair

Co-chairs are responsible for conducting meetings, accepting agendas and minutes, overseeing the group's activities, ensuring that the SIG objectives are met, and leading the SIG. The co-chairs shall serve for a term of office of two years and can be re-elected. If you are interested in being co-chair of the ACTA CQR SIG, please briefly outline where you work, your professional background or qualifications, current role and why you're interested in being co-chair.

Submissions to be sent to: natalie.shalit@acta.au. Deadline for submissions: April 14th.