

# The Benchmark

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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 **sixth** edition of the Benchmark. The ACTA CQR SIG has grown to represent **90 registries** and **140 individuals**, and these figures continue to grow! In December 2024 the Hub identified **125 clinical registries**: our aim is to grow the SIG to sign up every single one. **We encourage new CQRs to sign up.** To do this, please **email [acta@acta.au](mailto:acta@acta.au)**.

Our newsletter this month features a spotlight on the **Australian Breast Device Registry (ABDR)**.

The **ACTA 2024 Clinical Trials and Registries Symposium**, held in Melbourne from 2-4 December, was another great success. We would like to congratulate everyone who presented an oral abstract or a poster and, in doing so, contributed to the success of our yearly event. Highlights of the meeting are on the next page.

## Registry Spotlight



The **Australian Breast Device Registry (ABDR)** is a Clinical Quality Registry that commenced in 2012, with national rollout in 2014. It is a Commonwealth Funded and Monash University-led health initiative that records health data relating to breast device surgery. The registry aims to monitor the long-term safety and performance of breast implants, breast tissue expanders, acellular dermal matrices and other breast device-associated meshes. The registry identifies and reports on possible trends, complications, and quality of surgery involving these breast devices

The ABDR recently published its **8th Annual Report** that demonstrates substantive progress in addressing the registry's aims by accruing **98,460** patients, **113,439** procedures and **192,706** devices. In the current reporting period, **239** health services and **443** clinicians participated in the registry and the ABDR maintains a low opt-out rate at approximately 1%.



The 2023 Annual Report includes new analyses related to cosmetic tourism, use of matrix/mesh in cosmetic procedures, and overall revision rate variation. The ABDR thanks all participating clinicians and patients for their support.

# The ACTA 2024 Clinical Trials and Registries Symposium - Wrap Up

The ACTA 2024 Clinical Trials and Registries Symposium was held over 3 days from 2nd - 4th December at the Pullman Hotel, Albert Park. It was an action packed event that included one day fully dedicated to Clinical Registries, as well as four workshops covering Fundamentals of impact for registries (repeated), Translating registry outputs into community resources to improve health, and Reporting Patient Reported Measures for quality improvement purposes in Australian Clinical Quality Registries. Over **120** individuals attended the workshops, with over **180** attending the full day Symposium. Many enjoyed the networking opportunities during the session breaks as well as the Tuesday evening Soiree.

The Clinical Registry Program was developed and led by a hard-working Organising Committee comprising members across many different Clinical Quality Registries. Of 50 abstracts submitted, 18 were accepted for oral presentation, with 27 posters for viewing.

Feedback following the event showed that Workshops in particular were very highly rated, with **95% saying that they would recommend the workshops to a colleague**. Nearly **90% plan to attend the CQR symposium again in 2025**.

We also received valuable and thoughtful feedback regarding further improvements that can be made to the program in future years.

I extend my thanks to all who participated in the Symposium, including presenters, audience members, the sponsors and exhibitors, the Organising Committee members, the ACTA team, the Commonwealth Department of Health, and the staff at the Pullman for all their hard work to make the event such a successful one. We look forward to seeing you all again next year!



## Best Poster Award



The Best Poster Award for 2024 was awarded to **Sherine Sandhu** from the **National Gynae-Oncology Registry (NGOR)** for her poster entitled “The acceptability and feasibility of collecting patient reported measures in an ovarian, tubal and peritoneal cancer clinical quality registry”. We asked her:

### Q. What is your professional background?

My background is in patient decision-making and creating resources to support informed choice. I recently completed my PhD at the University of Melbourne which involved developing and evaluating a fertility preservation Decision-Aid. Prior to my research career, I worked in risk management consulting at a large professional services firm.

### Q. Why and how did you get into the Registry Sector?

My interest in women’s health and improving patient outcomes led me to join the National Gynae-Oncology Registry (NGOR). In addition, the role stood out as a great opportunity to incorporate my various skill sets, and continue to engage in meaningful research.

### Q. What is your role?

My role as Program Coordinator for the NGOR is highly diverse. Activities can range from creating patient materials and annual reports, to stakeholder engagement, process improvement and research activities. I am also overseeing the implementation of PROMs/PREMs into our registry. As we are still in our early stages, it has been incredibly valuable learning from other registries about their approaches and experiences with this.



### THE GOOD CQR TRAINING GUIDE

Finalisation of the **Good CQR Training Guide** has been delayed pending recruitment of a project officer, This has now been completed, and the Guide and Training Module activities will recommence in January 2025.

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

The **Australian Commission on Safety and Quality in Health Care** (the Commission) has released new [fact sheets](#) to support implementation of the [Australian Framework for National Clinical Quality Registries 2024](#). The fact sheets are tailored to CQR operators, clinicians and health service operators. They provide an overview of the Framework, best-practice guidance to establish and operate CQRs in Australia and links to essential resources to support effective implementation. Please share these resources with anyone in your network who may find this information of use. The Framework was recently featured in the Medical Journal of Australia. You can read the full article on [MJA Insight](#).

The Commission also has commenced a process to review and upgrade the [Australian Register of Clinical Registries](#) platform. As part of the review, a consultation process will be held with stakeholders to generate ideas and feedback to inform the new design. Further information about how you can be involved will be available soon. [Register your interest](#) to receive updates about the Commission's CQR projects or email the Commission [CQR@safetyandquality.gov.au](mailto:CQR@safetyandquality.gov.au) for any further information.

## Registry Publications

- Skelton K, Gorayski P, Penfold S, Murray A, Hamilton D, Yeo A, Jessop S, Hwang E, Dass J, Le H. Australian Particle Therapy Clinical Quality Registry (ASPIRE) protocol (TROG 21.12): a multicentre prospective study on patients with rare tumours, treated with radiation therapy. *BMJ Open* 2024; 0: e083044. doi: 10.1136/bmjopen-2023-083044
- **High quality care reduces hip fracture mortality:** Researchers working with the Australian & New Zealand Hip Fracture Registry have found that adherence to the ACSQHC Hip Fracture Clinical Care Standard reduces patient mortality. Where patients received hip fracture care that met five or six out of six key quality indicators, they had a 60% lower short-term mortality risk, while those meeting four indicators saw a 40% reduction. **Read the paper:** Harvey, L., Taylor, M.E., Harris, I.A., Mitchell, R.J., Cameron, I.D., Sarrami, P. and Close, J. (2024), Adherence to clinical care standards and mortality after hip fracture surgery in New South Wales, 2015–2018: a retrospective population-based study. *Med J Aust*. <https://doi.org/10.5694/mja2.52470>; **Listen to the [Hipcast podcast](#)** discussing the findings.

## Registry Milestones

- The **2023 Victorian Lung Cancer Registry (VLCR) [Annual Report](#)** provides insights into newly diagnosed lung cancer patients between January and December 2023 across 19 health services (51 hospitals) in Victoria.
- The **Lymphoma and Related Diseases Registry (LaRDR)** released their **[Annual Report](#)** for 2023-2024 online to highlight the progress on the registry, projects and publications.

## Recent Event News

### 2024 ANZ REDCap User Day

The 2024 ANZ REDCap User Day, held on 28 October 2024 at Monash University as a one-day event, brought together a vibrant community of REDCap users and administrators from various Australian and New Zealand institutions.

With 100 onsite attendees and 200 online participants, the event featured multiple speakers who showcased diverse applications of REDCap. The event received high satisfaction ratings, with the majority expressing enthusiasm and interest in attending future events.



The **Lymphoma and Related Diseases Registry (LaRDR)** co-hosted an annual investigator meeting with the Australasian Lymphoma Alliance (ALA, clinician-researchers) and Lymphoma Australia (LA, patient advocates) on October 29, 2024 in Brisbane. The theme for the meeting was “Working together to improve lymphoma patient outcomes”. They presented updates on the work of the ALA, LaRDR, and LA and involved a panel discussion. Over 90 people attended onsite and virtually. Click [here](#) for photos and more information.

## Health Information Managers Survey Invitation

**Professor Monique Kilkenny** is leading this survey and study regarding health information management roles in Australian clinical registries.

To complete the online survey please follow this link:

<https://redcap.link/himsurvey>

### Health Information Management roles at Australian Clinical Registries

**We want to hear from health information managers working at Australian clinical registries to explore your roles and responsibilities.**

#### Who can participate?

- Aged 18+ years
- Qualified health information manager
- Currently working at an Australian clinical registry; or
- Have worked at an Australian clinical registry in the last 5 years

#### What is involved?

Complete a 15-20 minute anonymous online survey about your role at an Australian clinical registry

**Contact us:** [monique.kilkenny@monash.edu](mailto:monique.kilkenny@monash.edu) or [catherine.burns@monash.edu](mailto:catherine.burns@monash.edu)



PRINCIPAL INVESTIGATOR: PROF MONIQUE KILKENNY  
APPROVED BY MONASH UNIVERSITY HUMAN RESEARCH  
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To start:

Scan the QR code or visit:  
[redcap.link/himsurvey](https://redcap.link/himsurvey)

The **SAHMRI Registry Centre** is delighted to announce in March 2025 it will host two events: Pre-symposium **Datathon** and **Annual Symposium**. The information regarding these events has just been released with the ability to register and submit an abstract. More information is available on the SAHMRI website using the above links.

SAHMRI REGISTRY CENTRE

# Datathon

19TH MARCH 2025

Join our Interactive Datathon Event

Submit an expression of interest to participate in an interactive Datathon event with up to 60 like-minded individuals. If selected, participants will work together in teams to solve a clinical question through applying data science tools and analytical techniques using health datasets.

SAHMRI Auditorium, North Terrace Adelaide, SA 5000

SAHMRI.ORG.AU/2025-SAHMRI-REGISTRY-CENTRE-DATATHON

HOSTED BY SAHMRI Registry Centre

KEY DATES

- 10th of January 2025 Expression of interests close
- 31st of January 2025 Notification of successful applicants

Proudly supported by ANZDATA & ANZICS Registries

Datathon winners have the opportunity to present at the Symposium

VISIT OUR WEBSITE

More information on the SAHMRI Registry Centre Symposium 20th March 2025 Visit [sahmri.org.au/2025-sahmri-registry-centre-symposium](https://sahmri.org.au/2025-sahmri-registry-centre-symposium)

SAHMRI REGISTRY CENTRE

# Annual Symposium

20TH MARCH 2025

Advancing Healthcare Through Registry Data & Analytical Insights

Exploring how advanced registry analytics transforms registry data into actionable insights

HOSTED BY SAHMRI Registry Centre

SAHMRI Auditorium, North Terrace Adelaide, SA 5000

KEYNOTE

PROFESSOR ANNE DUGGAN  
CEO Australian Commission on Safety and Quality in Health Care

Healthcare variation, clinical quality registries and using data to drive improvement

PLENARY

PROFESSOR GINNY BARBOUR  
Editor-in-Chief, Medical Journal of Australia

The key role of reporting and publication of findings of variation in clinical outcomes

ABSTRACTS NOW OPEN

- 10th of January 2025 Abstract Applications close
- 31st of January 2025 Notification of successful applicants

VISIT OUR WEBSITE

SAHMRI.ORG.AU/2025-SAHMRI-REGISTRY-CENTRE-SYMPOSIUM

Discover the first-ever Registry Centre Datathon on the 19th of March! Learn more [sahmri.org.au/2025-sahmri-registry-centre-datathon](https://sahmri.org.au/2025-sahmri-registry-centre-datathon)

SAHMRI Registry Centre

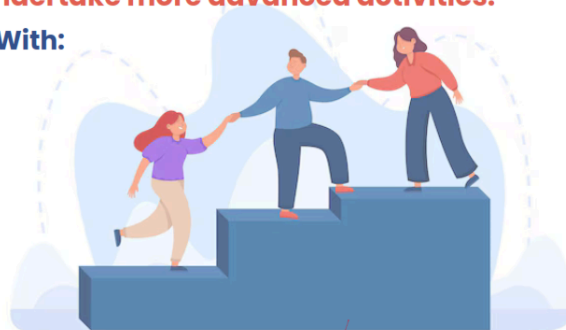
# Clinical Quality Registry ADVISORY SERVICE

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!

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Australian Clinical Trials Alliance