

# 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 (the Registry SIG), and is also published on the ACTA website.

## FROM THE EDITORIAL TEAM

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Welcome to the **fourth** edition of the Benchmark. The Registry SIG has grown to represent **90 registries** and **134 individual members**, and these figures continue to grow! In December 2023 the Hub identified **112 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](mailto:acta@acta.au).

Our newsletter this month features a spotlight on EXCEL, a care (ICU) registry, and news about the 2024 Registry ASM. An educational webinar occurred on **26th June** with senior presenters from the Australian Commission on Safety and Quality in Health Care and the Australian Department of Health and Aged Care: **'Enhancing Healthcare through Quality Registries and Digital Health'**. We hope you enjoyed the webinar. If you weren't able to attend, please be advised that a recording will be available on the ACTA website. The event was a resounding success with over 100 people attending. We would like to thank the presenters for their time and look forward to further updates.

**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 ASM. More news on the next page.

## Registry Spotlight

**EXCEL** - The Australian and New Zealand Extracorporeal Membrane Oxygenation (ECMO) Registry was established in 2019 to monitor the outcomes of ECMO patients.



Image of an ECMO machine

**Extracorporeal membrane oxygenation (ECMO)** is a life-saving procedure used when all other forms of life-support have failed, taking the place of a patient's heart and/or lungs. It is invasive, expensive and has a high risk of complications such as stroke, major bleeding, nerve damage and amputation. EXCEL investigators led an international Delphi study that created a core outcome set for ECMO patients. The registry harmonised Australian ECMO data collection and reports Clinical Quality Indicators (mortality, complications and patient-reported outcomes) on over 2000 patients to clinicians, hospitals and government to improve patient care.

The EXCEL Registry has **30 participating hospitals in Australia and New Zealand**

Within the registry there are five embedded randomised trials, including a



biobank for precision medicine, rehabilitation and a new platform trial. EXCEL links with international registries to allow clinical trials to be embedded at international sites. A manuscript on 6-month outcomes following ECMO was published in *Lancet Resp Med* and the first registry-embedded RCT is under review. For more information including to view publications, please view <https://www.monash.edu/medicine/sphpm/excel/home>



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## DEVELOPMENT OF THE GOOD CQR TRAINING GUIDE

Monash University and SAHMRI collaborated with an impressive working group comprising 31 members from several clinical quality registries, health services and government agencies, to develop the **Good CQR Training Guide** as an alternative, more pertinent resource on registries to the Good Clinical Practice training for clinical trials. The document is almost finalised and will be sent to the Department of Health and Aged Care for feedback. Following completion of the Guide, work on an online training module will commence, during the second half of the year. We would like to thank all who took part and provided their time to complete this important guide.

## CQR Impact stories - ECMO survivor

Our very first impact story comes from the **EXCEL** Registry. An ECMO survivor paves the way for an Australian ECMO peer support group. Prior to the establishment of the EXCEL Registry, clinicians measured extracorporeal membrane oxygenation (ECMO) patient mortality rates, but did not measure patient recovery after hospital discharge.

Through 6 and 12-month patient-reported outcome measures, the EXCEL Registry discovered that ECMO survivors can suffer physical disability, cognitive changes, anxiety, depression and long-term unemployment.

Craig Dicker received ECMO for 67 days. He and his family understand that 'talking with family and friends was important for everyone's recovery as we had been through trauma.'

Craig is part of the EXCEL management committee. The Dicker family are co-funders of the registry and have been involved in clinical quality projects and embedded trials. They have advocated for an Australian ECMO peer support group to enable people to connect and share experiences. The EXCEL ECMO peer support group proposal seeks \$107,000 in funding over three years to commence regular meetings nationally. For more information please contact Professor Hodgson at [carol.hodgson@monash.edu](mailto:carol.hodgson@monash.edu)



*In the photograph: Craig Dicker (second from left) and ECMO survivors met at the 2024 EXCEL Symposium and reiterated the need for an ECMO peer support group.*

## Registry Milestones

- The **Australian Diabetes Clinical Quality Registry (ADCQR)** recently published its 2023 Annual Report, featuring outcomes from 25 centres across Australia and 1426 patients. A must read for anyone in the sector! You can find the report at: <https://www.monash.edu/medicine/sphpm/adcqr/publications>
- The **Australian Breast Device Registry (ABDR)** has captured procedures from over 100,000 patients
- The **Australasian Pelvic Floor Registry (APFPR)** was established in 2019 to monitor the safety and quality of care relating to pelvic floor procedures to treat stress urinary incontinence and pelvic organ prolapse including those that use pelvic mesh. The commencement of the registry coincided with the COVID-19 pandemic which saw Category 3 elective surgeries cancelled. By March 2022, a total of 53 patients had been recruited from 4 hospitals in Australia. In June 2024, the APFPR achieved a momentous milestone of crossing 1000 patient registrations from 35 hospitals, with 900 surgeries and 450 PROMs responses recorded in the registry database. Soon the registry is poised to become binational with New Zealand signing up to participate.

## ACTA 2024 Clinical Trials and Registries Symposium

We are delighted that we will team up with our colleagues at ACTA to deliver a joint conference in 2024. **The ACTA 2024 Clinical Trials and Registries Symposium** will take place in **Melbourne** between **2-4th December** at the Pullman Melbourne Albert Park Hotel. To nominate for the Organising Committee for the Registries Component, please email [sarah.fraser@acta.au](mailto:sarah.fraser@acta.au). You need to be working within a CQR and commit to attending the event. We would love you to register your interest in the Symposium early at: <https://clinicaltrialsalliance.org.au/events-forums/2024-acta-clinical-trials-symposium/>

# Registry Publications

## Australasian Leukaemia and Lymphoma Group (ALLG) National Blood Cancer Registry (NBCR):

- **'How comparable are patient outcomes in the "real-world" with populations studies in pivotal AML trials?'** Tiong, I.S., Wall, M., Bajel, A. et al. Blood Cancer J. 14, 54 (2024). <https://doi.org/10.1038/s41408-024-00996-x>. The ALLG NBCR is a real-world evidence dataset that includes source information on morphology, flow, cytogenetics, and molecular features linked to treatment received, response, and survival outcomes. The ALLG NBCR dataset has been leveraged in the recent project titled 'How comparable are patient outcomes in the "real-world" with populations studies in pivotal AML trials?', resulting in the publication of the final manuscript to Blood Cancer Journal in March 2024. The study utilised data from **942 acute myeloid leukemia (AML) participants** that were consented and enrolled to the ALLG NBCR between 2012-2018, and **aimed to address concerns regarding the control arm of clinical trial populations and their generalisability to real-world AML outcomes**. Age and disease-matched control and interventional populations from published randomised trials were assessed, and the study analysis highlighted important notable differences in real-world outcomes when compared to clinical trial populations – overall, survival outcome among comparable cohorts captured in the ALLG NBCR appeared similar to, or superior to the control arm of clinical trials examining the benefit of adding midostaurin, GO, CPX-351, oral azacitidine or venetoclax. If you require any further information regarding either the publication or the ALLG NBCR please contact [nbcrcr@allg.org.au](mailto:nbcrcr@allg.org.au).

The **Lymphoma and Related Diseases Registry (LaRDR)** has the following recent publications:

Manuscript

- Barraclough A et al. **Impact and utility of follicular lymphoma GELF criteria in routine care: an Australasian Lymphoma Alliance study**. Haematologica. <https://doi.org/10.3324/haematol.2023.284538>

Conference abstracts

- Wang L et al. **The Definition and Use of Bulk Disease in Phase 3 Lymphoma Trials: A Comprehensive Literature Review**, Abstract Library at: European Hematology Association; 2024 June 13-16, Madrid, Spain.
- Chung E et al. **Definition and Use of Bulky Disease in Lymphoma Care: A Study from the Australasian Lymphoma and Related Diseases Registry (LaRDR)**, Abstract Library at: European Hematology Association; 2024 June 13-16, Madrid, Spain.
- If you would like your publications related to safety and quality, or annual reports published in the Australian Commission on Safety and Quality in Health Care newsletter 'On the Radar' (<https://www.safetyandquality.gov.au/publications-and-resources/resource-library/radar-issue-654>), please submit them for consideration to Dr Niall Johnson, editor, at [Niall.Johnson@safetyandquality.gov.au](mailto:Niall.Johnson@safetyandquality.gov.au)

## Strategic activity - updates

### Consumer friendly resources - update

The SAHMRI Registry Centre has partnered with the Registry for Senior Australians (ROSA), The Australian Corneal Graft Registry (ACGR) and the Transcatheter Aortic Valve Implantation Registry (TAVI-R) to translate complex registry outputs into consumer-friendly resources.

Funded by the Department of Health and Aged Care, the project is piloting a community co-design process, where members of the Consumer-Friendly Information Consumer Group will work with the Registry Centre to develop new resources designed for consumers, by consumers. These resources will enable consumers to make better-informed decisions about their healthcare and will be widely shared in the places where consumers seek healthcare information.



The Centre has held the first co-design workshop, with monthly meetings to be held over the next 12 months. How-to guides documenting the process will be accessible on the Centre website, enabling other registries to replicate the process.



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# Strategic activity - updates

## REGISTRY BASED TRIALS

Project update: the School of Public Health and Preventive Medicine, Monash University project to develop guidance for the conduct of registry-based trials is funded by the Commonwealth Department of Health and Aged Care. The project is moving into the next stage: **a systematic scoping review of the literature** is almost complete, and **ethics for this work has been approved**, and key informant interviews with stakeholders experienced in registry-based trials have begun. These two components will feed into a National Meeting where examples of good practice will be highlighted, challenges will be identified, and methods and approaches to inform the guide will be discussed. The team are looking to engage registry operators, clinicians, trialists and others at this national meeting; experience with registry-based (or other) trials is not required. For further information on the project please see: <https://www.monash.edu/medicine/sphpm/registries/registry-based-research/developing-a-best-practice-guide-for-registry-based-trials>

### To register to attend the National Meeting

**DATE:** 31 July 2024, 9:30am – 4:30pm AEST

**LOCATION:** Ground Floor, 553 St Kilda Road, Melbourne VIC 3004 (Zoom link for remote participation)

**RSVP:** by 19 July 2024

Funding support to attend: project funding enables financial support for a limited number of face-to-face attendees with expenses for airfare (up to \$500) and accommodation (up to \$250). To apply for travel support, please contact: [regtrialguide@monash.edu](mailto:regtrialguide@monash.edu). Valid tax receipts are required.

Please register here: <https://www.eventbrite.com.au/e/national-meeting-for-registry-based-trials-registration-913683480887>

## BEST PRACTICE PROMS REPORTING PROJECT

The aim of this project is to develop a set of guiding principles and recommendations for clinical quality registries (CQRs), clinicians and health service managers for consideration in the reporting of PROMs data to providers for quality improvement purposes, including analysis, reporting and interpretation of hospital or clinician-level PRMs from CQRs. Developed in collaboration with partners across CQRs, this document presents a framework and recommendations to guide the collection, analysis, reporting, and use of PROMs and PREMs. Next steps will involve piloting and validation of newly developed recommendations. This will be conducted in three phases: 1) Piloting and validating the initial guidelines with clinicians, sites, jurisdictions and registries; 2) Adapting the guidelines to a consumer audience; and 3) Developing accompanying practical resources for patients and clinicians.

The final set of clinician-focused and consumer-focused guidelines and the accompanying material will be disseminated via the ACTA Registry Special Interest Group and presented at various national forums and conferences with the potential to lead to national consistency in PRMs reporting from CQRs for quality improvement purposes.

## EXPANDING BEST PRACTICE IN REGISTRY SCIENCE

SAHMRI recently surveyed member registries, to inform and shape the development of several strategic registry related projects. Analysis of the results and refinement of the report is currently underway. Incorporating the ACSQHC Framework [1] and Department of Health and Aged Care National Strategy Priorities [2], the member survey was designed to address the needs of the following projects:

- Increasing CQR sector capability in public reporting: Inform current reporting practices, barriers faced and what supports are required to comply with best practice.
- Piloting a CQR Advisory Service: Evaluate where registries go to seek advice/support and the types of support preferred.
- Increasing CQR value and impact case studies and analysis: Determine if registries measure the outcomes and impacts of the outputs that they produce.
- Increasing CQR sector capability in data linkage: Describe the current linkage activities and experiences of Registry Centre member registries.
- Consumer engagement: Determine the level of consumer involvement within registries, identify areas where registries require assistance and evaluate gaps in material relevant for the public.

[1] ACSQHC. Framework for Australian clinical quality registries - a national standard for clinical safety and quality data collections and reporting Second Edition. Sydney : Australian Commission on Safety and Quality in Health Care, 2022.

[2] DHAC. A National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030. Sydney : Department of Health and Aged Care, 2021.