





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 SIG).

FROM THE EDITORIAL TEAM

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Welcome to the **third edition** of the Benchmark. The SIG has grown to represent **89 registries**, with **128 individual members**. The Hub have identified 112 clinical registries; it is exciting to see many new registries becoming active in the sector! We encourage members to invite other registries and registry colleagues to sign up. To do this, simply email acta@acta.au. As awareness of the Collaboration Hub grows, we receive an increasing number of enquiries from professionals who collaborate with registries (academics, quality improvement professionals, industry representatives and clinicians), wishing to be involved in the sector. In discussions with the Department of Health and Aged Care, the Collaboration Hub funder, we propose maintaining the membership of the SIG exclusively for those within the sector, *and* to broaden our communications reach to a wider ranging group of stakeholders. We will discuss this in more detail at the next webinar. In view of this growth, we are featuring some of the newer member registries in this edition. **Don't miss the Department of Health and Aged Care announcements about new finding opportunities!**

To contribute to the newsletter, please email the editor: claudia.lassetter@monash.edu

Registry Spotlight

Established in 1973, the Australasian Leukaemia & Lymphoma Group (ALLG) is Australia and New Zealand's only not-for-profit blood cancer clinical trial research group. In 2012 the ALLG created the **National Blood Cancer Registry (NBCR)** to detail the longitudinal clinical pathway for patients suffering from blood cancer, and links real-world demographic, cytogenetic, molecular, treatment and clinical outcome data for each participating patient. Participants may also opt-in to contribute samples under the NBCR, which are stored at the ALLG Biobank for future research purposes.

The NBCR recently achieved a substantive milestone of registering over 4000 participants to the study, from 49 contributing sites across Australia and New Zealand. This achievement marks 50 years of progress in blood cancer research through ALLG, and will allow for greater leverage of the



NBCR dataset and tissue samples in future research endeavours to improve patient outcomes. The NBCR operations team is featured below. **For more information please contact NBCR@allg.org.au** or visit www.allg.org.au



L-R: Madeleine Foreman - ALLG Data Manager, Karin Dunne - ALLG NBCR and Biobank Coordinator, Jenny Collins - ALLG NBCR Project Manager, Martina Chiarezza - ALLG Project Officer
Images provided by the NBCR



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Registry Showcase

The **Australasian Shunt Registry** is a population based, bi-national clinical quality registry established and operated by the **Neurosurgical Society of Australasia**. Its primary purpose is to systematically collect information related to the **use of cerebrospinal fluid (CSF) shunts** to guide best practice clinical processes, to improve health outcomes for patients with CSF shunts. Data collection commenced in December 2016. CSF is produced in the brain and serves as protection for the brain and spinal cord. CSF also circulates nutrients and chemicals filtered from the blood and removes waste products from the brain. Hydrocephalus is a neurological condition occurring when the CSF balance is disrupted causing accumulation and pressure on the brain. Hydrocephalus can be congenital or acquired. Left untreated, hydrocephalus can cause severe disability and even death. Hydrocephalus cannot be cured but it can be treated. The most common treatment is the insertion of a shunt. CSF shunts have high complication and failure rates, often requiring multiple revisions. Shunt dysfunction and complications have a clinical and economic impact on patients and the health system.

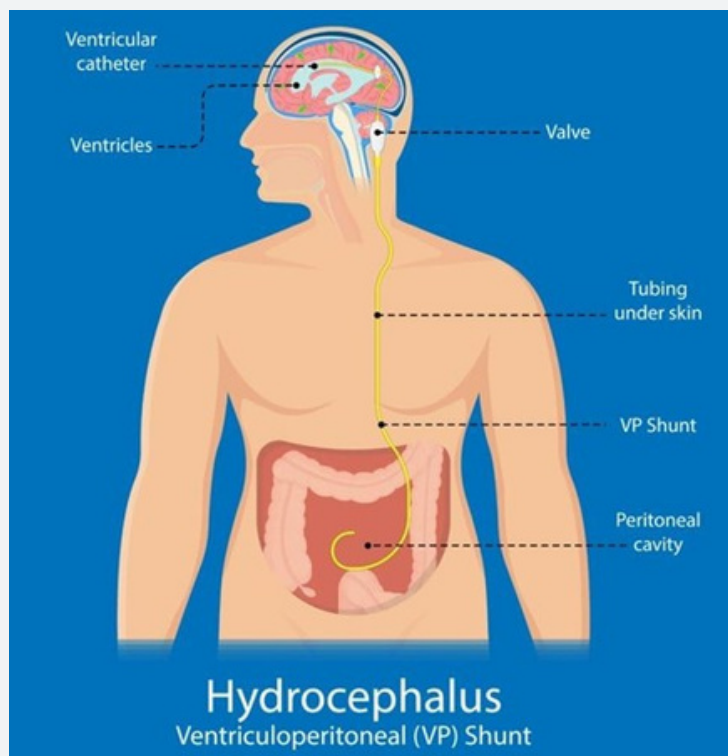


Image supplied by the Shunt Registry

Patient Population:

- 6195 admissions in the Registry for 4511 unique patients.
- 62.8% of admissions are over the age of 18 at the time of surgery
- Haemorrhage is the most common aetiology of the CSF disorder followed by congenital hydrocephalus

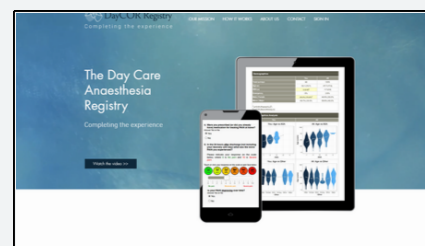
- 368 patients have had three or more surgical admissions since data collection commenced.

The 2023 annual report will be published in June. For further information visit www.nsa.org.au, or contact Katrina Smith, Shunt Registry Manager on shunt.registry@nsa.org.au.

The **Day Care Outcomes Recording Registry (DayCOR)** was established in 2018, to capture outcomes related to **day care procedures that involve an anaesthetic**. Outcomes are captured via a 15-Question survey sent to each patient 24 hours post discharge covering PROMs and PREMs, specifically, as an example:

- Need contact or return to hospital
- Pain level
- Post discharge nausea and vomiting (PDNV)
- Sleep disturbance
- Confusion, falls

Image of the DayCOR website.



Reporting is provided to all hospitals, private hospital groups, health departments and to the community as required by ACSQHC requirements. For more information contact Dr Ken Sleeman via www.daycorregistry.com.au

Registry Publications

Data from the Australian Stroke Clinical Registry (AuSCR) and the Australasian Rehabilitation Outcomes Centre (AROC) were recently linked to gain an enhanced understanding of the patient journey in stroke including acute care, rehabilitation and outcomes. Data linked from 2014-2017 includes 8,000 patients common to both registries. Ethics approval and approval from each of the registries' data governance committee was obtained. A recent publication highlighted two-thirds of patients required communication support to participate in healthcare activities and the importance of communication-accessible stroke care environments. (<https://www.tandfonline.com/doi/full/10.1080/10749357.2023.2279804>)

Shaw, B., Chung, E., Wellard, C., Yoo, E., Bennett, R., Birks, C., et al, (2024), **Poor outcomes for trial-ineligible patients receiving polatuzumab for relapsed/refractory diffuse large B-cell lymphoma in routine care: An Australian Lymphoma and Related Diseases Registry project.** eJHaem, 1-8. <https://doi.org/10.1002/jha2.870>



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New Strategy activities

PROJECT 1: CONSUMER FRIENDLY RESOURCES

Alongside the national best practice projects, the SAHMRI Registry Centre has been funded to deliver the Consumer Friendly Information (CoFI) project. This project directly involves three SAHMRI Registry Centre members – the Registry of Senior Australians (ROSA), the Transcatheter Aortic Valve Implantation Registry (TAVI) and the Australian Corneal Graft Registry. The project aims to **create and disseminate easily understandable and reliable treatment and outcome information** direct from registries, to empower consumers and their families to make informed decisions about their health. The project will also develop a series of guides to assist other registries implement similar processes and develop further consumer friendly resources.

PROJECT 2: REGISTRY BASED TRIALS

Increasing connectivity and integration between CQRs and clinical trials through registry-based trials forms part of Strategy Pillar 6: Priority 23. Monash University is collaborating with a wide range of CQR operators and researchers to compile a national best practice Guide on the use of national CQRs as a platform for clinical trials. The Guide will be published in December 2024. For more information, please contact Tsharni Zazryn at tsharni.zazryn@monash.edu.

PROJECT 3: EXPANDING BEST PRACTICE IN REGISTRY SCIENCE

Increasing CQR sector capability in public reporting

Increased public access to CQR data forms part of Strategy Pillar 5: Priority 20. The SAHMRI Registry Centre is working to improve public reporting activity across its member registries and translate these findings into a set of public-facing best practice resources. They are also investigating the feasibility of using a centralised national platform to host CQR public reporting in line with Strategy Pillar 1: Priority 5. Recommendations will be provided to the Department for further consideration.

Increasing CQR sector capability in data linkage

Facilitating strategic data linkage projects between CQRs and administrative data forms part of Strategy Pillar 6: Priority 22. The SAHMRI Registry Centre is leveraging the experiences and lessons learnt from their multiple member registries, including the National Joint Replacement Registry, the Registry of Senior Australians, and the Australia and New Zealand Dialysis and Transplantation Registry, to develop public facing CQR data linkage guidance resources. They will also collaborate with other national registries with experience in data linkage processes.

Piloting a CQR Advisory Service

Increasing communication and collaboration within the CQR sector forms part of Strategy Pillar 3: Priority 15. A part of the broader work on a CQR Communication and Collaboration Hub, the SAHMRI Registry Centre is piloting a CQR Advisory Service. This will enable Australian registries to seek support from, and leverage the expertise of, the SAHMRI Registry Centre. They will deliver a pilot evaluation report and recommendations to the Department for further consideration.

Increasing CQR value and impact case studies and analysis

Assessing contributions of CQRs to improvements in clinical practice and patient outcomes forms part of Strategy Pillar 2: Priority 9 and Strategy Pillar 4: Priority 18. It will also inform the evaluation of the Strategy and the National CQR Program. The SAHMRI Registry Centre is compiling a suite of standard metrics and case studies that measure the value and impact of its member registries. These will be shared with the Department and included in registry reporting.

For more information on the projects above (except where advised otherwise) please contact Cindy.Turner@sahmri.com



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DEVELOPMENT OF THE GOOD CQR TRAINING MODULE

Monash University is developing a 'Good CQR Training Module' as an alternative to the current Good Clinical Practice training for clinical trials. A guide is expected to be published in July 2024. This work builds upon the previously completed *Streamlining CQR Site Approval Pilot*. It is anticipated that the guide will be delivered in two phases: a comprehensive written guide to be developed this fiscal year, and an online training module to be developed during the first half of the next. The CQR Collaboration Hub has assembled a formidable team of experts to assist in the delivery of the guide, comprising representatives from 20 registries - covering a multitude of clinical domains - as well as health services, medical colleges, clinicians and registry related academics.

Registry News

ANNUAL REPORT RELEASES

- **National Cardiac Registry (NCR)**, captures outcome data relating to Percutaneous coronary intervention (PCI or angioplasty with stent). [Download here](#)
- **The Australasian Pelvic Floor Procedure Registry (APFPR)** captures outcomes related to the safety and efficacy of pelvic floor procedures in women. [Download here](#)
- The **Australian Cystic Fibrosis Data Registry (ACFDR)** provides a comprehensive insight into the complexities of cystic fibrosis (CF) in Australia. [Download here](#)

Australian Diabetes Clinical Quality Registry (ADCQR). In March 2024, the National Association of Diabetes Centres (NADC), a division of the Australian Diabetes Society, announced an award in honour of the Australian Diabetes Clinical Quality Registry (ADCQR) Lead: Professor Sophia Zoungas, for her contribution to quality improvement. The 2024 NADC Sophia Zoungas Quality Improvement in Diabetes Services Award (QIDSA) is a prestigious award that aims to recognise organisations that have demonstrated significant improvements in diabetes management or have secured additional funding or services through their utilisation of ADCQR data as a quality improvement tool.

The NADC are offering two awards to reflect the contributions from various health care settings in diabetes care; a Primary Care service award and Secondary/Tertiary or Centre of Excellence award. This is an annual award and winners will be announced at the Australasian Diabetes Congress each year.

More details available at:

<https://nadc.net.au/nadc-awards-qidsa/> The ADCQR 2023 Annual Report

will be published in May. Image supplied by the NADC.



Appointments



From L to R - Senior Project Officer Sarah Eley, Centre Director Cindy Turner, and Project Manager Tamara Hooper.

The SAHMRI Registry Centre is delighted to appoint:

- **Project Manager Tamara Hooper and**
- **Senior Project Officer Sarah Eley**



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Australian Government Update

The **National Clinical Quality Registry Program** is underway. If you wish to be notified of any new funding opportunities, please register your interest on AusTender and Grant Connect and regularly check the Department's website: <https://www.health.gov.au/our-work/national-clinical-quality-registry-program>.

The Stream 1 funding opportunity is now open on [AusTender](#). **Applications close at 2.00 pm Monday 20 May 2024**. The latest [communiqué](#) is also available.

Recent Publications

- The **[Digital Health Blueprint](#)**, a ten-year vision for digital health to drive a more connected and sustainable health system.
- The **[National Digital Health Strategy](#)** 2023-2028, 5-year plan that sets the vision and pathway for our digital health future.

Events and Courses

SAHMRI Registry Centre Seminar #1 2024

In February the SAHMRI was fortunate to host Professor Ingrid Sketris as guest speaker for the Registry Centre's first seminar for 2024. Professor Sketris presented on the Canadian Network for Observational Drug Effect Studies (CNODES): using distributed data networks to improve drug safety and effectiveness.

SAHMRI Registry Centre Scientific Symposium 2024 took place on Thursday 28th March 2024.

Theme: Value and Impact of Clinical Quality Registries – Catalysts for Change in Policy and Practice.

International Speaker: Dr Freddie Bray, Head of Cancer Surveillance Branch, the International Agency for Research on Cancer (IARC) World Health Organisation.

UPCOMING COURSES

Patient Reported Outcome Measures (PROMs) for Clinical Registries

An introductory one-day course, designed for clinicians, researchers, registry coordinators and other healthcare professionals planning to or currently collecting PROMs, is based on a conceptual framework model and guidelines for the use of PROMs in clinical registries. Join leading academic Dr Rasa Ruseckaite on this short course, providing an overview of topics ranging from methodological development through to dissemination of PROMs data. Date:

28th May 2024 Location: **online via Zoom** Time: [Click here to register](#)

Advanced Workshops on Real-Time Dashboards and AI Applications for CQRs

Following the insightful feedback from a post-event survey of the 2023 ASM workshop, it's clear that professionals in the clinical registry sector are keen to further develop their skills in two pivotal areas of **dashboarding and Artificial Intelligence**. The School of Public Health and Preventive Medicine at Monash University is thrilled to announce two upcoming workshops: "**Automating Interactive Reporting Using R**" set for July 2024, and "**AI for Clinical Quality Registries: Unlocking Insights for Enhanced Healthcare**" scheduled for October 2024. These sessions are specifically designed to enhance your capabilities in automated reporting and applying AI in healthcare, respectively. Both workshops require a basic working knowledge of R or Stata, and we're offering a one-hour refresher session prior to each workshop to brush up on your skills. If you're eager to dive deeper into these critical areas and join us for a blend of theoretical and practical learning experiences, we encourage you to express your interest by contacting us at Med-ClinicalRegistries@monash.edu. This will ensure you receive all the necessary updates and more details about the workshops.

CQR COLLABORATION HUB WEBINAR

The next webinar to be organised through the ACTA Clinical Quality Registry Special Interest Group will be scheduled in May 2024. The CQR Collaboration Hub executive will provide an update on the strategic projects mentioned in this newsletter, and also share other updates. A special guest speaker will be in attendance. More news to come!



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