

# The Benchmark

*The Benchmark is a collaboration between Monash University Clinical Quality Registries, the South Australian Health & Medical Research Institute (SAHMRI) Registry Centre and the Australian Clinical Trials Alliance (ACTA).*

## FROM THE EDITORIAL TEAM

Welcome to our first ever edition of the Benchmark, the Australian Registry Sector newsletter, which will be published quarterly. So much has happened in the last year! We reinvigorated our ACTA Registry Special Interest Group (SIG) in June 2022, with a vision to increase the membership and deliver value for the sector through educational webinars, a first class ASM, and from hereon, quarterly newsletters. This newsletter is for you, the community of people who work in Clinical Quality Registries.



Professor Stephen McDonald (SAHMRI)



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## REGISTRY SHOWCASE



### VLCR

**Operated by:** Monash University School of Public Health and Preventive Medicine

**Key personnel:** Margaret Brand, Udani Samankula, Prof John Zalberg and Assoc Prof Rob Stirling

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**The Victorian Lung Cancer Registry** was established in 2011 with the purpose of improving outcomes in lung cancer in Victoria. The **VLCR** captures data from **19 health services** including **49 hospitals** and has over **19,000 patients** registered. The **VLCR** provides a **quality indicator report** to participating institutions reporting clinical performance against **22 quality indicators**, enabling benchmarking for local institutional evaluation and service innovation and secondly a generic report providing broad contextual details to the greater lung cancer community

Since 2013, there have been significant improvements in key indicators such as presentation to a lung cancer multidisciplinary meeting across the state, which may well contribute to improved survival rates during this period.



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## ACTA UPDATE

We recently welcomed a number of new colleagues from ACTA:

**Dino Cercarelli**, Chief Operating Officer, brings over 10 years of senior leadership and research operations experience to ACTA in both the pharmaceutical and healthcare sectors. He focuses on organisational growth strategies while being across current and future trends to ensure set strategies are aligned and achieved. Dino places great emphasis on communication and relationship building with key stakeholders. He is also passionate about building and fostering an organisational culture which is embraced and driven by employees.

**Amanda Richmond**, Project Manager, was appointed to ACTA in July 2023. Amanda manages ACTA's project portfolio and is dedicated to continuous improvement and delivering high-quality outcomes.

We also sadly farewellled **Michael Mihatsch**, who worked tirelessly to support registries through the ACTA Registry SIG.

We would like to express our sincere gratitude to him and wish him all the best in his new role at the Australasian College for Emergency Medicine.



## APPOINTMENTS



The Australasian Pelvic Floor Procedure Registry (**APFPR**) and the Australian Breast Device Registry (**ABDR**), jointly announce the appointment of **Natalie Heriot** as Senior Manager, Surgical Registries.

## REGISTRY VACANCIES

**Senior Project Officer - National Cardiac Registry**, closes 17th October (get in quick!) <https://www.linkedin.com/jobs/view/senior-project-officer-at-alfred-health-3731268794/?originalSubdomain=au>

For more information about the NCR, <https://nationalcardiacregistry.org.au/>

## REQUEST FOR ASSISTANCE

The ACTA Registry SIG, led by co-chairs Professors Ahern and McDonald, invite you to participate in a national survey, the preliminary results of which will be shared at the **2023 Australian Registry Annual Scientific Meeting**, at Monash University on the 20th October. The survey aims to inform the development of a maturity framework for Australian clinical quality registries (CQRs). It asks about registry characteristics that are associated with specific registry outputs/outcomes.

The survey takes only 5 minutes to complete. It is completely voluntary. To participate, please contact [acta@acta.au](mailto:acta@acta.au)

## REGISTRY PUBLICATIONS



- **The challenges facing Australia's underfunded and underappreciated clinical registries** by Professor Susannah Ahern, **InSight+ (Medical Journal of Australia's doctors news publication)**, October 2023
- Doherty, D.A., S.Y.C. Tong, J. Reilly, J. Shrapnel, S. McDonald, S. Ahern, I. Harris, C.S. Tam, A.L. Brennan, C. Hodgson, L. Wilcox, A. Balagurunathan, B.E. Butcher, and C.M. Reid, **Registry randomised trials: a methodological perspective**. *BMJ Open*, 2023. 13(3): p. e068057



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## EVENTS

### SAHMRI Registry Centre Workshop July 2023

The **SAHMRI Registry Centre Workshop** held in July 2023 provided a valuable experience for attendees when the invited speaker Professor Tim Beukelman, MD, MSCE, a founding member and current Scientific Director of the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Registry, presented the topic: Using a Prospective Observational Registry to Produce Real World Evidence Suitable for Pharmaceutical Companies and Regulatory Agencies – The CARRA Experience. Professor Beukelman informed the audience of the CARRA experience, a prospective observational registry that has enrolled more than 12,000 children with arthritis, lupus, and dermatomyositis at 70 clinical sites in the United States and Canada. The Registry has collaborated with multiple pharmaceutical companies to conduct post-market (phase IV) safety studies and report on real-world medication use and effectiveness.

## UPCOMING EVENTS

### 2023 Australian Clinical Registry ASM - Melbourne 19th/20th October 2023

Congratulations to the Organising Committee for creating yet another jam-packed program with representation from the registry sector Australia-wide. For more details, click here:

<https://clinicaltrialsalliance.org.au/latest-news/2023-australian-clinical-registry-annual-scientific-meeting-innovation-for-impact/>.

The 2023 ASM includes two workshops:

- Data to Action: Leveraging automated interactive reporting for CQR
- Communication approaches to maximize CQR Impact

### SAHMRI Registry Centre Symposium 2024

Planning is now underway for the SAHMRI Registry Centre Symposium 2024. Potential dates for the 2024 Symposium are: Thursday March 21st and Thursday March 28th. More information will be available soon.

**The Myeloma and Related diseases Registry (MRDR) Annual Breakfast Meeting** is on Monday, 6 November, 7:00 to 8:15 am at the Melbourne Convention and Exhibition Centre before the Blood 2023 sessions at 8.30am. Presentations include new developments and progress of the ANZ and APAC MRDR, the MY-PROMPT-2 trial and EpiMAP. All are welcome!

To register <https://www.eventbrite.com.au/e/myeloma-and-related-diseases-registry-interest-group-breakfast-meeting-tickets-700095302897>

**The Lymphoma Breakfast Meeting** is co-hosted by the Australasian Lymphoma Alliance (ALA), Lymphoma and Related Diseases Registry (LaRDR) and Lymphoma Australia (LA) on Tuesday, 7 Nov 2023 7:00 AM - 8:30 AM AEDT. The theme for the meeting is "Working together to improve lymphoma patient outcomes". We will present updates on the work of the ALA, LaRDR, and LA.

To register: <https://www.eventbrite.com.au/e/alalardrla-lymphoma-breakfast-meeting-tickets-694424601677>

# REGISTRY NEWS

The **Registry of Senior Australians (ROSA)** is delighted to advise that they have been announced as a **finalist** for the Data Innovation Award (2023 Research Australia Awards). In its third year, the Award is presented to an individual or team that has developed the most innovative method of gathering, making available, processing or interpreting data in a way that advances health and medical research, including matching of data and data sets which have not previously been linked.

The **SAHMRI Registry Centre** is delighted to collaborate with Dr Jessica Orchard, Senior Research Fellow, School of Public Health and NHMRC Emerging Leader Fellow, The University of Sydney, supporting the development of an emerging registry, the **Australasian Registry of screening ECGs of National Athletes (ARENA)**. The purpose of ARENA is to collate cardiac screening records of athletes, which are conducted by sports organisations across Australia and New Zealand, to identify conditions associated with **sudden cardiac death (SCD)** in elite athletes. This will be achieved by developing the ARENA Registry to facilitate current and future research on cardiac outcomes of screened athletes.

The SAHMRI Registry Centre welcomes **ASPIRE**. The **Australian Particle Therapy Clinical Quality Registry - ASPIRE** has been established at the South Australian Health and Medical Research Institute (SAHMRI) to investigate long-term cancer outcomes of patients receiving conventional x-ray therapy (Photon) compared to Proton Beam Therapy (PBT). ASPIRE is a prospective, observational, longitudinal study of paediatric, adolescent young adult and rare adult tumour patients from a select group of tumour streams treated with radiation therapy.

ASPIRE is a key component of the Australian Bragg Centre for Proton Therapy and Research, the first PBT treatment facility in Australia.

The aim of ASPIRE is to provide a source of evidence to provide increased certainty around the claim that PBT is of superior safety compared to conventional photon radiotherapy.

The **Florey Institute of Neuroscience and Mental Health** is developing a new, world-class national digital clinical quality registry platform on stroke care: **The Australian Stroke Clinical Registry (AuSCR)**. The four-year grant is being provided as part of the MRFF 2022 Research Data Infrastructure Grant opportunity (MRFFRDII000059). The strategic partnerships for this proposal provide a use case in stroke to:

- Establish the urgently needed data linkage solutions for the automated transfer of data from hospitals into a national Clinical Quality Registry platform;
- provide data tools (e.g. dynamic dashboards) to increase the use of registry data by clinicians,
- create a novel National Stroke Research Data Asset linking the registry data and datasets held by the Australian Institute of Health and Welfare to enable contemporary research in stroke, including care access and patient outcomes.

For further information contact: Jot Ghuliani, Australian Stroke Data Tool Program Manager, [jot.ghuliani@florey.edu.au](mailto:jot.ghuliani@florey.edu.au) or Dominique Cadilhac, Project Lead and AuSCR Data Custodian, [dominique.cadilhac@florey.edu.au](mailto:dominique.cadilhac@florey.edu.au).

## REGISTRY MILESTONES

The **Australian Breast Device Registry (ABDR)** Australia's largest repository of information about breast device surgery has reached an important milestone, capturing details of more than **100,000 procedures**.

Established as a binational CQR in 2012, the **Bariatric Surgery Registry of Australia and Aotearoa New Zealand** has reached the milestone of **150,000 participants enrolled**.