

The Benchmark

Contact Us
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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). The newsletter is circulated to members of ACTA's Registry Special Interest Group.

The 2023 ASM included:

- **welcome drinks**
- **two workshops**
- **a full day conference**
- **a best poster award.**



We exceeded our attendance target of 150 participants, featuring 33 speakers, 22 presentations and over 20 posters. Feedback included **93% of attendees saying they would 'recommend the ASM to a colleague'** and **90% stating they 'will attend again next year'**; the quality of the program and content of presentations was deemed highly informative and varied.

In response to member demand, we also ran our first workshops. They received excellent feedback, with demand for more topics next year.



Dr Reza Pourghaderi,
Instructor of the Data Workshop

The editorial team would like to thank the organising committee for their tireless work in developing such a great quality program.



ASM hosts: Professors Ahern and McDonald with Head of the School of Public Health (Monash), Professor Sophia Zoungas.

FROM THE EDITORIAL TEAM

Welcome to the **second edition** of the Benchmark, the Australian Registry Sector newsletter, published quarterly. The **2023 Australian Clinical Registry ASM**, held in Melbourne on the 19th-20th October, was a 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. We look forward to seeing you all in January for our next webinar. We wish you all a restful holiday season.

Professor Susannah Ahern (Monash)



Professor Stephen McDonald (SAHMRI)



Claudia Lassetter (Monash)



Cindy Turner (SAHMRI)



ASM Highlights

We did it again!

The **2023 Australian Clinical Registries ASM** was our biggest and best ever!



Read on for the highlights.

ASM Organising Committee, with 12 members from all over Australia representing 20 CQRs.



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Medical Research Institute



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Clinical
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Alliance

The ASM was held at the Education hub in the Alfred Hospital, enabling registration fees to remain at \$200, providing exceptional value for money. Feedback from attendees suggested it might be time to choose a purpose-built venue, as attendances continue to grow. The CQR collaboration Hub will consider this, noting that the costs of venue hire and Audio-visual support would result in higher costs. Sponsorship arrangements are being considered to offset these.

Best Poster Award



The Best Poster Award was launched at the 2023 ASM. We interviewed award winner Joanne Kennedy, from the Australian Hand Difference Register.

Q. What is your professional background?

After completing a Bachelor of Science, I worked in the assisted reproductive technology (ART) sector in London. I then completed my Master of Genetic Counselling at the University of Melbourne and have worked at the Murdoch Children's Research Institute ever since.

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

I fell into the registry sector. A colleague at the AHDR approached me, it was still in its infancy. I worked with the team based at The Royal Children's Hospital (RCH) to expand it nationally. I fell in love with what I was doing and have remained so ever since.

Q. What is your role?

I am a Senior Project Coordinator. This involves liaising with the families on the register, the wide range of healthcare professionals that recruit their patients to the register, and the AHDR team. Essentially, I am the "go to" person if anyone has a question.

Featured, to the right: Joanne Kennedy, of the Australian Hand Difference Register. The prize consisted of \$750 towards travel and conference costs.



ACTA Update

ACTA recently appointed two project officers, **Sarah Fraser** and **Vivian Klaver**, who will work across the Clinical Quality Registries SIG. We look forward to meeting them at the Registry SIG Webinar in January.

Australian Government Update

The Australian Government is establishing a **National Clinical Quality Registry Program**. 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>.

For more information, please contact cqrpolicy@health.gov.au

Australian CQR Maturity Survey



Recently, the CQR Collaboration Hub invited SIG Registry members to participate in a national survey, the preliminary results of which were shared at the **2023 Australian Registry Annual Scientific Meeting**, on the 20th of October. We had an outstanding response from the SIG, with **over 70% of registry members responding** and we extend our thanks to all respondents. We set ourselves a goal to increase registry responses by reaching out to non-SIG member registries listed on the Commission's Register of Registries. We have since extended the invitation to all registries we were able to contact. Results will be submitted for publication early in 2024.

About the survey

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 aruna.kartik@monash.edu.

Registry contact details

We encourage all registries to verify their contact details on the Commission's Register of Registries. If you need to update them, please email CQR@safetyandquality.gov.au



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Registry Publications

- Inacio MC, Davies L, Jorissen R, Air T, Eshetie T, Mittinty M, Caughey G, Miller C, Wesselingh S. **Excess mortality in residents of aged care facilities during COVID-19 in Australia, 2019-2022.** International Journal of Epidemiology. Accepted November 2023.
- Sluggett JK, Air T, Cations M, Caughey GE, Ward SA, Ahern S, Lin X, Wallis K, Crotty M, Inacio MC. **Clinical quality indicators for monitoring hospitalizations among older people with dementia accessing aged care services.** Journal of Alzheimer's Disease. In press October 2023.
- Davies LW, Air T, Jorissen RN, Mittinty M, Caughey G, Wesselingh S, Inacio MC. **Historical trends and future projections of demand for permanent residential aged care for older people in Australia, 2008- 2052.** Journal of the American Medical Directors Association. In press October 2023.

Upcoming Events

- **ACTA Registry SIG Webinar:** Featuring the NSW Agency for Clinical Innovation. January 18th, 9am-10:15am AEDT.
- Dr Chris Davies from the **Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)** convenes the SAHMRI Statistics Education Forum and welcomes all members. This is a monthly online meeting for presentations of research or journal article discussions related to statistics in registry science. If you would like to join the mailing list for these meetings, or are interested in presenting at a future meeting, please contact **Chris2@anzdata.org.au**
- **SAHMRI Registry Centre Annual Symposium 2024**

Don't miss out on this premier Registry Sector event, hosted by SAHMRI. All SIG members warmly invited!

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

Date: Thursday 28th March 2024
Symposium: 9:30am – 4:30pm
Cocktail event: 4:30pm – 6:30pm

Please use this link to register:
<https://www.trybooking.com/events/landing/1159058>

KEYNOTE
SPEAKER



Dr Freddie Bray
Head of Cancer Surveillance
Branch, The International Agency
for Research on Cancer (IARC),
World Health Organization

SPEAKERS



Prof Danny Liew
Dean and Head of Adelaide Medical
School, Adelaide University



Prof Caroline Miller
COO, SAHMRI | Executive Director,
Health Policy Centre



Prof Ian Harris
Orthopaedic Surgeon,
University NSW



Prof Gillian Caughey
Associate Director, ROSA, SAHMRI



Dr Paul Secombe
Intensivist, Director of Alice Springs
Hospital ICU | Director, ANZICS
CORE Adult Patient Database

SAHMRI REGISTRY CENTRE
SCIENTIFIC SYMPOSIUM
2024 PRESENTS

Value & Impact of Clinical Quality Registries

*Catalysts for change in
policy & practice*

THURSDAY 28 MARCH
9:00AM – 4:30PM
SAHMRI AUDITORIUM

Registrations open from 8:30am.
Networking cocktails in SAHMRI
foyer from 4:30pm to 6:30pm.

[CLICK TO REGISTER](#)

Registration is kept to a minimal cost of
\$75 thanks to the generous support of
SAHMRI. All food and drink included.

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Registry Showcase



Australian Hand Difference Register (AHDR)

Operated by: Murdoch Children's Research Institute

Key personnel: A/Prof David McCombe, Jo Kennedy, Dr Daniel Wilks, Prof Tony Penington, Rose Biggins

Phone: (03) 9936 6766

Email: ahdr@mcri.edu.au

Website: www.mcri.edu.au/ahdr

Congenital hand differences are a range of conditions presenting at birth, occurring when the formation of the upper hand and/or arm is somehow affected during fetal development and later growth, resulting in absence, abnormality, duplication, undergrowth or overgrowth of part or all of the hand and/or arm. Affecting approximately 1 in 600 children, these differences can become a lifetime challenge affecting the child's function and appearance. The Australian Hand Difference Register (AHDR) was established in 2017 with the generous support of the McNally Family Foundation, The Australasian Plastic Surgery Foundation, and Aussie Hands, a not for profit that provides support, information and encouragement to people born with a hand difference and their families. The AHDR now has 20 recruited sites across Australia, including major paediatric hospitals and private clinics.

How can I join the AHDR?

If your child was born with a hand or arm difference, they can be included on the AHDR with your consent. Please contact us to send you a Participant Information Statement and Consent Form if this has not already been arranged by your health care practitioner.

Useful websites

- AHDR: mcri.edu.au/research/projects/ahdr
- Aussie Hands: aussiehands.org
- AFPS: plasticsurgeryfoundation.org.au

Murdoch Children's Research Institute
The Royal Children's Hospital, 50 Flemington Rd
Parkville, Victoria 3052 Australia
P +61 3 9594 7664
F +61 3 9348 1395
W mcri.edu.au
Mm 21 006 566 972

Contact us

For further information, please do not hesitate to contact us.
Phone: (03) 9936 6766
Email: ahdr@mcri.edu.au
Post: AHDR, PO Box 907, Parkville, VIC 3052

Australian Hand Difference Register

Working in partnership with:
The Murdoch Foundation, The Australasian Plastic Surgery Foundation, Aussie Hands

The AHDR provides data, generating momentum in research and education about this complex and varied group of conditions. It enables Australian clinicians to collaborate with the international clinician community, to enhance joint knowledge and expertise. Researchers are able to observe and analyse patterns such as prevalence and outcomes, as well as make comparisons across different populations within Australia and internationally.

Grant announcements

Health Translation SA (HTSA). HTSA Medical Research Future Fund (MRFF) Catalyst Grant Scheme. Empowering Carer and Older People Dyads: Characteristics and Impacts on Quality of Care and Unplanned Hospitalisations. Chief Investigators: Eshetie T, Yu S, Sluggett J, Dawkins C, Schulze M, Caughey G, Inacio M. Funding period: 08/11/2023-08/11/2024.

Appointments



The **National Cardiac Registry (NCR)** announces the appointment of **Ray Stewart**, senior project officer, who recently relocated from the UK, where he managed national clinical registries for the Intensive Care National Audit and Research Centre (ICNARC).

The **Australian Breast Device Registry** welcomed **Dr Yvonne Chow** to the Steering Committee, taking over from Dr Gillian Farrell as Clinical Lead for the Australian Society of Plastic Surgeons (ASPS).

Positions vacant



The **National Cardiac Registry (NCR)** has a position available for a project officer. Applications close on 20th January 2024.

<https://www.livehire.com/careers/alfredhealth/job/RGMXH/ERZW8IQ07/project-officer>

Registry Milestones

The **Australian Diabetes Clinical Quality Registry (ADCQR)**, established in 2023 collected its first data on **1,500 adults living with diabetes** from **25 participating health services** providing diabetes care across Australia. The ADCQR finalised and disseminated its first site reports in December 2023; the annual report will be available in early 2024. For more information, please email: adcqr@monash.edu or visit:

<https://www.monash.edu/medicine/sphpm/adcqr>

The **National Cardiac Registry** has exceeded **72,000 cases**, and **57 hospitals contributing**, including, for the first time, 21 private hospitals. The Registry is pursuing a model of direct hospital data contribution, which will see an increase in hospital participation in 2024 and beyond. The Annual Status Report will be available early in 2024. Contact details: www.nationalcardiacregistry.org.au

To contribute to the next edition of The Benchmark please email claudia.lassetter@monash.edu