



MONASH
University

MONASH
CLINICAL REGISTRIES
PORTFOLIO 2019

MONASH
PUBLIC HEALTH AND
PREVENTIVE MEDICINE

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I am delighted to share with you this updated Monash Clinical Registries Portfolio which showcases the diverse range of clinical registries housed within our School. Clinical registries drive high-quality, equitable healthcare in a cost-effective way. We are therefore proud to administer 35 distinct registries, as well as managing associated activities including international collaborations, clinical trials and registry harmonisation projects.

As the clinical lead of the Australian National Diabetes Audit (ANDA), I have first-hand insight into the role of clinical registries in benchmarking best practice, and in providing an evidence-base on which to guide health policy and clinical research.

Highlights for this year include our new EXCEL Registry, focusing on the use of extracorporeal membrane oxygenation (ECMO), which has developed incredible relevance during the COVID-19 pandemic, and the new Australasian Pelvic Floor Procedure Registry, which we hope will monitor problems associated with pelvic mesh erosion, and improve outcomes for women having these surgeries.

I am excited about the number of registries now collecting Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs), which help researchers and clinicians understand what patients consider to be good outcomes, allowing us to work towards treatment goals that deliver the greatest impact on their lives. I am also passionate about the level of consumer involvement in the establishment and running of our registries, with an increasing number of our Steering Committees including consumer advocates.

I would like to thank the countless researchers, clinicians, healthcare professionals, administrative staff, registry staff, and consumer advocates that help administer these registries, contribute vital data or ensure registry findings are shared and translated into practice and policy. And importantly, I would like to thank the thousands of participants who generously share their experiences and health information with our registries, in order to improve the future care of others.

Professor Sophia Zoungas

Clinical Quality Registry Forum – October 2019

In October 2019, over 180 delegates attended the Clinical Qualities Registry Forum, titled '*Maximising Australian CQRs' potential to improve safety and quality*' which was held at Pullman on the Park, Melbourne. This event was hosted in partnership by Monash University's SPHPM, the Victorian Agency for Health Information, and the Australian Government Department of Health. A highlight for many was the keynote speaker, 'The highs and lows of building national outcomes registries – lessons and opportunities for Australia', presented by the Director of the Dutch Institute for Clinical Auditing, Dr Eric Hans Eddes, MD, PhD.



Professor Sophia Zoungas, Dr Eric Hans Eddes and Professor Susannah Ahern



Panel Discussion: What is needed to develop the role of CQRs in safety and quality

Who uses Clinical Quality Registry data?

The overarching purpose of Clinical Quality Registries (CQRs) is to improve the quality and safety of clinical care, through the collection, analysis and feedback of clinical outcomes to hospitals and clinicians. Once CQRs reach a level of maturity in relation to recruitment of hospitals and clinicians, and proportion of cases captured, they are incredibly valuable datasets for many purposes, including investigator initiated research, as aggregated reports for governments and their agencies, and for linkage with other clinical datasets. All requests for access to registry data are subject to individual registry data access policies that ensure robust governance, privacy of identified individuals, and alignment of the purpose of the request with registry aims and objectives.

In 2019, Monash Clinical Registries reported over **200 requests** for access to registry data and for the provision of ad-hoc reports. The Myeloma and Related Diseases Registry and Lymphoma and Related Diseases Registry between them had 30 requests for data. Professor Erica Wood, Academic Lead of Transfusion and Blood Diseases Outcomes Registries, noted that requests came from a range of sources, including clinicians and hospitals, investigators interested in conducting analyses of registry data, as well as industry and government.

Dr Jenni Williams-Spence, Program Manager of the Australian and New Zealand Society of Cardiothoracic Surgeons' Database, which had more than 20 requests for data, describes these requests as supporting research projects addressing key clinically relevant research questions. Examples include data linkages to external registries; requests for aggregate data to assist ANZSCTS members with presentations at conferences and industry meetings; ad-hoc reports for hospitals and individual surgeons to assess performance in relation to other sites or published standards; and to support a response to a review of Medicare Benefits Schedule items.

Professor Belinda Gabbe, Academic Lead for the Trauma and Emergency Registries, noted the significant number of requests for the Burns Registry of Australia and New Zealand (BRANZ; 14 requests). The requests predominantly relate to clinician projects, including regarding gender-specific outcomes following burn injury; burn injuries associated with epilepsy and seizures; scald burns from home hot water systems; and bacteraemia and multi-resistant organisms in adult burn patients. The BRANZ also supplied data to the Australian and New Zealand Burn Association Prevention Committee to highlight issues and educate on burn prevention and appropriate first aid as part of National Burn Awareness Month.



Clinical Quality Registries – leading health services research



Dr Ben Beck

While Clinical Quality Registries are primarily used to inform hospitals and clinicians of their clinical outcomes, they also make a significant contribution to real-world evidence through their collection of timely, standardised and highly granular clinical data. Monash Clinical Registries have been associated with at least 70 publications arising directly from clinical registry data or information in 2019, in addition to oral and poster presentations at local and international conferences and other academic forums.

Dr Ben Beck was the first author on five registry-related publications in 2019. In Dr Beck's study on traumatic spinal cord injury (TSCI) using data from the Victorian State Trauma Registry, he demonstrated that there was no reduction in the incidence of TSCI over a 10-year period. However, the incidence of TSCI resulting from low falls increased by 9% per year, and these events were particularly prevalent in older adults.

Dr Rasa Ruseckaite is the first author of the initial publication on a series describing the development of evidence-informed guidelines for patient reported outcome measures (PROMs) inclusion within CQRs in Australia. Dr Ruseckaite developed a conceptual framework that classified findings, from both the literature and the survey of Australian registries, into broad categories ranging from initial PROM development to PROM outcome dissemination, providing the structure for development of guidelines in the next phase of the project currently under way.

Monash Clinical Registries also provides leadership regarding registry-related issues and methods; examples include 2019 publications by Professor Ahern, Head of Registry Science and Research, and Mr Peter Lee, PhD student with CCRET.

Professor Ahern's publication '*Qualified privilege legislation to support clinician quality assurance: balancing professional and public interests*', published in the Medical Journal of Australia, discussed current legislation that aims to protect clinical audit activity from third-party disclosure, and recommended review of the legislation to better meet the needs of the increasingly significant CQR sector. Peter, whose 2019 publication was regarding a systematic review of economic evaluations of CQRs, notes that there is emerging evidence for the cost-effectiveness and return-on-investment attributed to CQR operation. However, few studies or reports were identified, and there were considerable variations across the evaluated CQRs highlighting the need for further studies.

For a full list of Monash Clinical Registries-related publications from 2019, see page 46.

CANCER OUTCOMES REGISTRIES



Dr Nathan Papa

— Head, Prostate Cancer Research



Professor John Zalcborg

— Head, Cancer Research Program

Prostate Cancer Outcomes Registry — Australia and New Zealand (PCOR-ANZ)

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Purpose/aims of the registry

The purpose of the PCOR-ANZ is to:

- monitor patterns of care for men diagnosed with prostate cancer
- ensure that care provided to men with prostate cancer is aligned with evidence-based guidelines
- assess the effectiveness and safety of prostate cancer procedures
- provide a platform for interventions aimed at improving survivorship following a diagnosis of prostate cancer

Population captured

Men diagnosed with prostate cancer in each Australian jurisdiction and from New Zealand.

Outcomes collected

Patient-reported quality of life, treatment, progression, survival and quality of care.

Year established

2013

Jurisdictions participating in 2019

Multiple sites in each of the following jurisdictions: Australian Capital Territory, Queensland, Tasmania, Victoria, New South Wales, Western Australia, South Australia, and New Zealand.

Reports published/provided in 2019

PCOR-ANZ 2018 Annual Report

Bi-national clinician, hospital, Integrated Cancer Service (ICS) and hospital group benchmarking reports

HREC Approval Number

MUHREC/21692

Number of data requests/ad hoc reports in 2019

6

PROMs/PREMs collected

Extended Prostate Cancer Index Composite – 26 questions (EPIC-26)

Funding source

Movember Foundation

Website

prostatecancerregistry.org

“All jurisdictions are participating with the exception of Western Australia. This is a bi-national registry which includes men with prostate cancer in Australia and New Zealand. Coverage has increased across all the jurisdictions for 2019, with the overall population coverage increased by 12% when compared with men diagnosed in 2017 and 2018.”

Prostate Cancer Outcomes Registry — Victoria (PCOR-VIC)

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Purpose/aims of the registry

The PCOR-VIC focuses on describing patterns of care following diagnosis of prostate cancer and monitoring quality of delivered care and whether it is in line with evidence-based guidelines.

Population captured

A population-based registry currently capturing 85 per cent of all newly diagnosed cases of prostate cancer in Victoria.

Outcomes collected

- disease-specific quality of life at 12 months post diagnosis/treatment
- treatment outcomes including positive margin rate post prostatectomy, documentation of clinical stage, PSA recorded post prostatectomy, advanced disease and active surveillance

Year established

2009

Jurisdictions participating in 2019

Victoria

Reports published/provided in 2019

Bi-annual clinician and hospital benchmarking reports.

HREC Approval Number

HREC/16/Alfred/98

Number of data requests/ad hoc reports in 2019

9 data requests

PROMs/PREMs collected

Expanded Prostate Cancer Index Composite – 26 Short Form (EPIC-26); EORTC QLQ PC-25; Utilisation of Sexual Medications/Devices questionnaire

Funding source

- Movember Foundation
- Cancer Australia
- Prostate Cancer Foundation of Australia
- Commonwealth Department of Health and Ageing

Website

monash.edu/medicine/sphpm/pcor-vic/home

TrueNTH Global Registry

The TrueNTH Global Registry aims to significantly improve the physical and mental health of men treated for prostate cancer by (i) examining the extent to which current practice in participating sites reflects evidence-based guidelines; (ii) systematically measuring clinical and patient-reported outcomes and key elements of care that have the potential to impact outcomes; (iii) comparing and sharing de-identified outcomes between participating sites; (iv) analysing variations to understand key drivers that deliver the best outcomes; and (v) mobilising the exchange of knowledge among the prostate cancer clinicians, treating facilities and men diagnosed with prostate cancer.

The Global Registry is funded by the Movember Foundation and has two main components – a Project Coordination Centre (PCC) and a Data Coordination Centre (DCC), both appointed following a competitive peer-review process. The PCC is based at the University of California, Los Angeles (UCLA) and the DCC is based at Monash University in Australia.

As the Data Coordination Centre (DCC), Monash University is the centre receiving and housing data transferred from 22 Local Data Centres (LDCs), representing more than 100 healthcare institutions across 15 countries. The DCC oversees data management and developed the TrueNTH Global Registry, its data dictionary and the protocol; built a technical solution for the secure transfer of data from sites to the DCC and is on an ongoing basis providing training to sites on its use. Monash provides a research portal to enable participating sites to gain secure access to data (following relevant ethical approval); and is producing quality indicator reports back to participating sites.

Upper Gastrointestinal Cancer Registry (UGICR)

Purpose/aims of the registry

The UGICR is a clinical quality registry which aims to identify variation in treatment and outcomes of individuals newly diagnosed with a primary cancer of the pancreas; oesophagus; stomach; liver; or biliary system.

The UGICR will provide benchmarked reports on agreed indicators of best practice to drive improvements in quality of care and patient outcomes.

Population captured

All people aged 18 years or older, who are diagnosed with pancreatic, oesophageal, gastric, liver (hepatocellular carcinoma) or biliary system cancer, that have been diagnosed, assessed or treated in a participating site.

The UGICR's pancreatic cancer module is active in sites across Victoria and New South Wales. The oesophagogastric cancer and biliary system cancer modules of the registry are underway at all participating Victorian sites. Development of the liver cancer module is planned to commence in 2020.

Outcomes collected

The UGICR collects information relating to patient diagnosis, treatment and outcomes; with additional data items collected for risk adjustment and patient demographics. The outcomes measured vary between modules.

In 2019, the UGICR began a pilot to collect patient-reported measures for participants with pancreatic cancer.

Year established

2015

Jurisdictions participating in 2019

Victoria and New South Wales

Reports published/provided in 2019

N/A

HREC Approval Number

15482A

Number of data requests/ad hoc reports in 2019

4

PROMs/PREMs collected

Pancreatic cancer module pilot: EORTC QLQ-C30 and PAN-26

Funding source

Victorian Government provided initial seed-funding for the UGICR. The Pancare Foundation and industry partners have also sponsored this registry. The registry is also supported by a related NHMRC project grant.

Website

ugicr.org.au

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National Gynae-Oncology Registry (NGOR)

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Purpose/aims of the registry

The NGOR is an Australian clinical quality registry that measures and monitors patterns of care following diagnosis of cancers of the female reproductive system. The aim of this registry is to identify variation in the treatments and outcomes of patients with newly diagnosed gynaecological cancers, and with benchmarked reports on agreed clinical quality indicators, it strives to drive improvements in quality of care and patient outcomes.

Population captured

A person is eligible to the NGOR if they:

- are 18+ years old
- have been recently diagnosed with a gynaecological cancer
- were diagnosed or received treatment for their cancer at a hospital that is participating in NGOR
- do not need an interpreter and/or are believed to understand written English

The registry's ovarian, tubal and peritoneal (OTP) cancer module is active in sites across Victoria, New South Wales, Tasmania and Western Australia. The endometrial, cervical and vulvovaginal cancer modules are in development.

Outcomes collected

The NGOR collects information relating to patient care pathways. For the existing module, some of the outcomes collected include:

- completeness of disease staging
- residual disease after debulking surgery
- appropriateness of treatment/care
- intra-operative and post-operative complications

Year established

2017

Jurisdictions participating in 2019

Victoria, New South Wales and Tasmania.

Reports published/provided in 2019

NGOR QI Report 2017-2019

HREC Approval Number

HREC/17/MonH/198

Number of data requests/ad hoc reports in 2019

0

PROMs/PREMs collected

N/A

Highlight

The NGOR's two-year Ovarian, Tubal and Peritoneal pilot was completed in 2019, with several additional gynaecological oncology specialists joining the Steering Committee, and recruitment of ~ 575 participants.

Funding source

- CASS ('Contributing to Australian Scholarship and Science') Foundation
- Ovarian Cancer Australia
- Australian Society of Gynaecologic Oncologists
- The Epworth Medical Foundation (The Audrey Voss Gynaecological Cancer Research Grant)

Website

ngor.org.au

“The NGOR was awarded The Audrey Voss Gynaecological Cancer Research Grant, enabling it to expand from an ovarian cancer registry to a multi-modular registry, covering Endometrial, Cervical and Vulvovaginal Cancers.”

Purpose/aims of the registry

The VLCR is a clinical quality registry that aims to measure and benchmark quality of care in newly diagnosed lung cancer patients at participating health services. Data collected are used to inform clinical practice and to facilitate continuous quality improvement in the care of patients with lung cancer.

Population captured

The VLCR aims to record all newly diagnosed lung cancer cases at participating sites in Victoria. The Registry captures patients who have been admitted to a participating health service and have had a diagnosis of primary lung cancer.

Outcomes collected

The VLCR provides risk-adjusted, benchmarked reports to participating sites to measure quality of care. Quality indicator reports sent to participating sites provide measures for:

- timeliness of care, including time from referral to diagnosis and diagnosis to treatment
- quality and access to treatment, including provision of evidence based assessment
- delivery of anti-cancer treatment
- multidisciplinary care coordination
- patient distress screening and supportive care

Year established

2012

Jurisdictions participating in 2019

The VLCR currently collects from 19 sites across metropolitan and regional Victoria, including public and private institutions.

Reports published/provided in 2019

2018 Quality Indicator Report

HREC Approval Number

HREC/16/Alfred/84

Number of data requests/ad hoc reports in 2019

Multiple site requests for their own data

PROMs/PREMs collected

Nil

Funding source

- MRFF
- DHHS
- Astra Zeneca
- Bristol-Myers Squibb
- Pfizer
- Boehringer Ingelheim

Website

vlcr.org.au

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CARDIAC OUTCOMES REGISTRIES



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Victorian Cardiac Outcomes Registry (VCOR)

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Purpose/aims of the registry

The VCOR was established in 2012 to ensure the safety and quality of cardiac based therapies across Victoria. As a clinical quality registry, VCOR monitors the performance of health services in both the public and private sectors.

Population captured

The VCOR has two separate modules currently collecting data of interest in cardiovascular care. These include a percutaneous coronary intervention (PCI) clinical quality registry and a Cardiac Implantable Electronic Device (CIED) module. The PCI and modules directly relate to management of coronary artery disease, primarily in its acute form (heart attacks and angina). All hospitals in Victoria performing PCI contribute data to the registry.

Outcomes collected

PCI outcomes:

- procedural success
- door to balloon times
- complications including cardiac, bleeding, neurological and renal
- mortality (in-hospital and 30 days post-procedure), including risk adjusted mortality at 30 days
- quality of life at 30 days post-procedure
- readmission 30 days post-procedure

CIED outcomes:

- device successfully implanted without in-hospital complications
- in-hospital cardiac arrest
- 30 day unplanned cardiac readmissions
- 30 day device related re-operations
- 30 day device related infection rate
- mortality (in-hospital and 30 days post-procedure)

Year established

2012

Jurisdictions participating in 2019

Victoria

Reports published/provided in 2019

- VCOR provides quarterly benchmarked quality reports to PCI participating hospitals and DHHS.
- VCOR provides biannual benchmarked quality reports to CIED participating hospitals.
- 2018 Annual Report.

HREC Approval Number

47/12

Number of data requests/ad hoc reports in 2019

20 data requests approved / 12 ad hoc reports provided

PROMs/PREMs collected

EQ5D at 30 days

Funding source

- The Department of Health, Victoria
- NHMRC Centre of Research Excellence in Cardiovascular Outcomes Improvement
- NHMRC Program Grant

Website

vcor.org.au

"The publication of the VCOR Risk Adjustment manuscript in the Journal of American College of Cardiology: Cardiovascular Interventions is the only published highly predictive risk adjustment model for 30-day mortality post-PCI that includes high-risk conditions of cardiogenic shock and out of hospital cardiac arrest."

Melbourne Interventional Group Registry (MIG)

Purpose/aims of the registry

The MIG Registry is a collaborative effort between six public hospitals in Melbourne and Geelong. The registry aims to provide reliable medium and long-term results (morbidity and mortality) of coronary interventions across Melbourne hospitals.

Population captured

Data on all patients undergoing a percutaneous coronary intervention (i.e. either an angioplasty or a stent) performed in participating hospitals are collected and entered into a central database.

Outcomes collected

Mortality – in-hospital, 30 day and longer term with linkage to the National Death Index. In-hospital complications including peri-procedural myocardial infarction, stent thrombosis, urgent coronary artery bypass grafts, and major bleeding readmissions to hospital within 1 month of procedure.

MIG published 11 manuscripts in 2019.

Year established

2004

Jurisdictions participating in 2019

Victoria

Reports published/provided in 2019

N/A

HREC Approval Number

92/04

Number of data requests/ad hoc reports in 2019

16 data requests approved / 8 ad hoc reports provided

PROMs/PREMs collected

EQ5D at 30 days

Funding source

- NHMRC Centre of Research Excellence in Cardiovascular Outcomes Improvement
- NHMRC Program Grant
- Device and Pharmaceutical companies

Website

monash.edu/medicine/sphpm/registries/mig

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Australian and New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS) Cardiac Surgery Database Program

Purpose/aims of the registry

The ANZSCTS Database aims to ensure a high standard of care for adult cardiac surgical patients is maintained across Australia and New Zealand through a peer reviewed quality assurance program, the production of comprehensive annual reports showing morbidity and mortality information and trends, and an active research program.

Population captured

The Program aims to capture all adult cardiac surgical procedures in Australia and New Zealand including coronary artery bypass grafts and valve procedures.

Specifically, the ANZSCTS Database includes patients who undergo:

- cardiac surgery and/or
- other thoracic surgery using cardiopulmonary bypass and/or
- pericardiectomy for constrictive pericarditis, where performed on or off cardiopulmonary bypass

Outcomes collected

- Mortality (in hospital or 30 days post-surgery)
- Complications including cardiac, neurological, renal, infections, gastrointestinal and return to theatre
- Readmissions within 30 days post-surgery

Year established

2001

Jurisdictions participating in 2019

Victoria, New South Wales, Australian Capital Territory, Queensland, Western Australia, South Australia and New Zealand.

Reports published/provided in 2019

National Annual Report 2018, NSW Annual Report 2018, Quarterly Peer Review Reports.

HREC Approval Number

262/09

Number of data requests/ad hoc reports in 2019

20+

PROMs/PREMs collected

N/A

Funding source

Public sector funding bodies and private/individual hospitals

Website

anzscts-database.org

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MEDICAL OUTCOMES REGISTRIES





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Australian National Diabetes Audit (ANDA) / Australian National Diabetes Audit Longitudinal Register (ANDA-L)

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Purpose/aims of the registry

ANDA is a well-established, important biennial, quality activity facilitated by the National Association of Diabetes Centres (NADC), in services providing care for people with diabetes across Australia.

Participating diabetes centres, including primary, secondary and tertiary care receive an individualised report of their patient data to compare with other diabetes centres. A pooled national report is an important source of cross-sectional data on the clinical status and outcomes of individuals attending services providing diabetes care across the country. The aim of ANDA is for diabetes centres to use this information for quality improvement and benchmarking purposes.

ANDA-L is a sub study of ANDA. It will prospectively follow up the same cohort of patients during the clinical data collection. This will allow participating centres to observe changes in clinical indicators for people with diabetes at both a group and individual level and offer a rich source of understanding of treatments, and clinical outcomes for people with diabetes. ANDA-L will also provide longitudinal descriptive reporting to participating centres for quality improvement and benchmarking purposes.

Population captured

ANDA: Patients aged 18 years and over with diabetes attending participating diabetes centres in Australia (presented as the primary analysis).

Patients aged less than 18 years with diabetes attending participating diabetes centres in Australia (presented separately for secondary subgroup analysis).

ANDA-L: Patients aged 18 years and over with diabetes attending participating diabetes centres in Australia.

ANDA and ANDA-L involves sites in the tertiary, secondary, primary, and community based sectors throughout Australia.

Outcomes collected

ANDA – There are two ANDA audits that alternate each year:

- **ANDA-AQCA** (Australian Quality Clinical Audit). This audit focuses on clinical indicators known to impact on the outcomes of the person with diabetes. 2019 delivered the ANDA-AQCA.
- **ANDA-AQSMA** (Australian Quality Self-Management Audit). This audit is more focused on self-management and diabetes distress, collecting data related to diabetes education, self-care practices and quality of life.

ANDA-L – 2019 delivered the baseline data collection of the ANDA-AQCA. This audit focuses on clinical indicators known to impact on the outcomes of the person with diabetes of which will be followed up in 2021.

Year established

ANDA: 2013

ANDA-L: 2019

Jurisdictions participating in 2019

ANDA

Victoria, New South Wales, South Australia, Western Australia, Queensland, Tasmania, Northern Territory and Australian Capital Territory.

ANDA-L

Victoria, New South Wales and Queensland. (Further promotion will be undertaken to the remaining jurisdictions in Australia prior to the next data collection period in 2021.)

Reports published/provided in 2019

ANDA

Australian National Diabetes Audit, ANDA-AQCA 2019 Annual Report; Australian National Diabetes Audit, ANDA-AQCA Site Report 2019 (specific to individual diabetes centre registered in this activity).

Australian National Diabetes Audit, ANDA-AQSMA Pooled Final Report 2018; Australian National Diabetes Audit, ANDA-AQSMA Site Report 2018 (specific to individual diabetes centre registered in this activity).

ANDA-L

ANDA-L baseline data has been incorporated within the ANDA dataset and reporting.

HREC Approval Number

ANDA – LNR/17/MonH/123

ANDA-L – HREC/48547/MonH-2019

Number of data requests/ad hoc reports in 2019

ANDA – No

ANDA-L – No

PROMs/PREMs collected

Blood glucose control, lipids, blood pressure, weight/height, foot related outcomes, eye related outcomes, urinary protein/albumin and diabetic emergencies

Funding source

Australian Government Department of Health

Website

monash.edu/medicine/anda

Australian Rheumatology Association Database (ARAD)

Purpose/aims of the registry

The Australian Rheumatology Association Database (ARAD) was established as a national arthritis database to provide valid and reliable longitudinal clinical data of people with inflammatory arthritis in Australia, with the ultimate aim of providing better care and improving outcomes for patients. The aims of ARAD were to establish a specific cohort of Australian patients with inflammatory arthritis receiving anti-tumour necrosis factor (TNF) and other biological disease modifying antirheumatic drug (bDMARD) therapies together with a group of patients not receiving bDMARDs to determine long-term safety and effectiveness of the biological therapies. It became operational in August 2003. The database is owned by the Australian Rheumatology Association.

Population captured

Patients with inflammatory arthritis including rheumatoid arthritis, ankylosing spondylarthritis, psoriatic arthritis and juvenile idiopathic arthritis are eligible to enrol in this voluntary registry. In the future we will also add patients with polymyalgia rheumatica, giant cell arteritis and other vasculitis.

Outcomes collected

The ARAD collects information from patients at six to 12 monthly intervals via paper-based and online questionnaires about medical history, medication history, responses to medication, physical functioning and quality of life. We also perform linkages to MBS and PBS data and state and national cancer and death registries.

Year established

2001

Jurisdictions participating in 2019

Australia

Reports published/provided in 2019

Annual – personalised for Rheumatologists

HREC Approval Number

Cabrini Human Research Ethics Committee: 12-23-04-01

Number of data requests/ad hoc reports in 2019

7

PROMs/PREMs collected

PROMs: Disease status, quality of life and physical function (Health Assessment Questionnaire (HAQ) (specific for each disease group), Assessment of Quality of Life Questionnaire (AQoL), SF-36, European Quality of Life and the Paediatric Quality of Life Inventory (for JIA), the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) (for AS)).

PREMs: Nil

Funding source

NHMRC Enabling Grant (2006 to 2012), unrestricted pharmaceutical company educational grants to the Australian Rheumatology Association and in kind support from Cabrini Institute, Monash University and University of Sydney and Royal North Shore Hospital.

Website

arad.org.au

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CLINICAL LEADS

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REGISTRY SCIENCE AND RESEARCH



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Australian Dementia Network (ADNeT) Registry

Purpose/aims of the registry

The Australian Dementia Network (ADNeT) brings together Australia's leading dementia researchers into a research and clinical network to create a sustainable, translational research infrastructure that enables ongoing, high quality research and clinical care for Australians living with, or at risk of, cognitive impairment and dementia. The ADNeT Registry is a clinical quality registry (CQR) that will track, benchmark and report on the quality of clinical care of people with dementia and mild cognitive impairment (MCI) to drive quality improvement, identify suitable and willing persons for clinical trials, and systematically collect longitudinal data for research on the determinants, epidemiology and trajectory of cognitive decline.

Population captured

All persons newly diagnosed with either dementia or mild cognitive impairment from participating memory clinics and individual medical specialists in Australia. The aim is to eventually expand to include all diagnostic settings and services for dementia. Recruitment commenced in March 2020.

Outcomes collected

Outcomes will include baseline clinical characteristics of persons with dementia or mild cognitive impairment and periodic follow-up clinical data. Information will also be collected from patients at baseline and carers at baseline and periodically via self-completed patient and carer surveys.

Data linkage will also be explored. Clinical indicators will measure quality of diagnosis, quality of care, access to supports, preventable complication and long term outcomes for persons with dementia.

Year established
2019

Jurisdictions participating in 2019
N/A

Reports published/provided in 2019
N/A

HREC Approval Number
44037

Number of data requests/ad hoc reports in 2019
N/A

PROMs/PREMs collected
Patient surveys will be conducted at baseline to collect outcome and experience data from patients.

Funding source
NH & MRC National Institute for Dementia Research Grant

Website
australiandementianetwork.org.au

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Australian Cystic Fibrosis Data Registry (ACFDR)

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Purpose/aims of the registry

The ACFDR aims to accurately characterise the demographics, morbidity and mortality of the CF population of Australia over time, use health information to increase awareness and advocate for patient resources, improve quality of care by reviewing and monitoring trends in outcomes by benchmarking CF centres in Australia and internationally, and monitor the impact of new therapies and changed treatment practices.

Population captured

All persons diagnosed with cystic fibrosis (CF) who attend participating specialist CF treatment centres in Australia. This is estimated to cover over 90% of patients diagnosed with CF nationally.

Outcomes collected

Birth and diagnostic data including genetic mutation status, clinical measures such as lung function and BMI status, pulmonary infections, disease complications, treatments, organ transplant, and death.

Year established

1996 (data collection commenced in 1998).

Jurisdictions participating in 2019

Victoria, Tasmania, Australian Capital Territory, New South Wales, South Australia, Western Australia and Queensland.

Reports published/provided in 2019

2017 Annual Report

2017 Centre Comparison and Trend reports

2017 Jurisdictional reports

HREC Approval Number

HREC/16/Alfred/187

Number of data requests/ad hoc reports in 2019

10

PROMs/PREMs collected

Nil

Funding source

- Cystic Fibrosis Australia
- Vertex Pharmaceuticals

Website

cysticfibrosis.org.au/dataregistry



Australian and New Zealand Thyroid Cancer Registry (ANZTCR)

Purpose/aims of the registry

The Australian and New Zealand Thyroid Cancer Registry (ANZTCR) is a clinical quality registry designed to monitor diagnosis, treatment and early post-operative outcomes for people with thyroid cancer at contributing hospitals in Australia and New Zealand. It is expected that this will inform understanding of the natural history of thyroid cancer, research, best practice and lead to improved patient outcomes and quality of care.

Population captured

All patients over 16 years of age with an initial diagnosis of thyroid cancer at a contributing hospital in Australia. The registry involves public and private health service sites throughout Victoria, New South Wales, South Australia and Queensland. The registry will also expand to include sites in New Zealand.

Outcomes collected

The ANZTCR collects information relating to diagnosis, surgery, pathology, treatment and outcomes, with additional data items collected for risk adjustment.

Year established

2017

Jurisdictions participating in 2019

Victoria, New South Wales, South Australia and Queensland

Reports published/provided in 2019

2018 Annual Report

HREC Approval Number

HREC/16/Alfred/61

Number of data requests/ad hoc reports in 2019

0

PROMs/PREMs collected

Nil – a PROMs acceptability study will be undertaken in 2020

Funding source

Australian and New Zealand Endocrine Surgeons (ANZES), industry, and the Alfred Foundation and Medtronic

Website

anztcr.org.au

ACADEMIC LEAD

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Binational Colorectal Cancer Audit (BCCA)

Purpose/aims of the registry

The Binational Colorectal Cancer Audit (BCCA) is a clinical quality registry established by the Colorectal Surgical Society of Australia and New Zealand (CCSSANZ). It was started as a clinical audit and is a surgeon-led surgical audit applicable to all surgeons who perform colorectal cancer surgery.

BCCA data is used for clinical audit of the surgical practices of Australian and New Zealand surgeons for the purpose of quality assurance. The audit also works towards creating a large dataset containing Australian and New Zealand data that can be used for research and quality improvement purposes, with the aim of advancing knowledge and understanding of treatment for colorectal cancer. By creating this dataset BCCA will be able to identify areas pertinent to patient safety, identify benchmarks and identify sites that may be performing outside the common bounds of the larger group.

BCCA collects information on patient and tumour characteristics, colorectal cancer management, complications of treatment, and clinical quality indicators relating to quality of surgical and hospital care.

Population captured

All patients 18 years or older undergoing resection or treatment for colorectal cancer at participating public and/or private hospitals.

Outcomes collected

The BCCA collects information relating to diagnosis, surgery, pathology, treatment and outcomes.

Year established

2007

Jurisdictions participating in 2019

All Australian States and New Zealand.

Reports published/provided in 2019

The 2018 Binational Colorectal Cancer Audit Report 2019

2018 Clinical Quality Reports to eligible sites

HREC Approval Number

Multiple HRECs including NMA

Number of data requests/ad hoc reports in 2019

8 data requests

PROMs/PREMs collected

No

Funding source

CSSANZ Members' annual subscription fee contribution; CSSANZ support; Royal Australian College of Surgeons; Epworth Health; and Medtronic for education and reporting initiatives.

Website

bowelcanceraudit.com

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Australian Spine Registry (ASR)

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Purpose/aims of the registry

The ultimate aim of the Australian Spine Registry (ASR) is to optimise quality of care for spine surgery patients. This will be achieved by:

- identifying variability in treatment amongst individuals undergoing spine surgery
- providing a tool for individual surgeons to complete audits of their spine surgery
- determining the degree of compliance with evidence-based guidelines for spine surgery
- identifying factors that predict favourable and unfavourable surgical outcome
- monitoring trends in surgical approach, choice and safety of implantable devices
- providing an infrastructure on which intervention or other studies can be established
- determining the results and functional effectiveness of specific spine surgeries in a 'real world' setting

Population captured

All patients over 18 years of age undergoing elective spine surgery.

Outcomes collected

The ASR collects information relating to diagnosis, treatment, and Patient Reported Outcome Measures (PROMs), with additional data items collected for risk adjustment. Clinical indicators are in development.

Year established

2017

Jurisdictions participating in 2019

Currently the registry is in a pilot stage. Recruitment commenced in January 2019. The pilot involves public and private health service sites in Victoria, New South Wales, Western Australia and Tasmania.

Reports published/provided in 2019

Australian Spine Registry Annual Report 2018

HREC Approval Number

HREC/16/MH/93

Number of data requests/ad hoc reports in 2019

Nil

PROMs/PREMs collected

EQ5D-3L; OSWESTRY Disability Index;
Neck Disability Index

Funding source

BUPA, Nuvasive, Zimmer Biomet, Stryker,
HCF, LifeHealthcare, Medtronic, DePuySynthes

Website

spineregistry.org.au



Purpose/aims of the registry

The Australasian Pelvic Floor Procedure Registry (APFPR) is a clinician-led national clinical quality registry. It is currently under development and will measure and report on surgical and patient reported outcomes related to procedures involving stress urinary incontinence (SUI) and pelvic organ prolapse (POP).

The APFPR will be rolled out in a modular format, with modules for SUI and POP involving mesh/prostheses being developed and piloted over the next 2 years, from mid-2020. These modules will particularly focus on device safety, complications, revisions and explantations.

Population captured

All patients undergoing relevant pelvic floor procedures for SUI or POP at contributing hospitals in Australia.

Outcomes collected

The APFPR will collect outcomes relating to SUI/POP diagnosis, comorbidities, surgery, and complications including revision and mesh removal details.

Additional data items will be collected for risk adjustment

Year established

2019

Jurisdictions participating in 2019

The registry is in development and has not commenced data collection.

Reports published/provided in 2019

N/A

HREC Approval Number

63247

Number of data requests/ad hoc reports in 2019

N/A

PROMs/PREMs collected

In development

Funding source

Commonwealth Department of Health

Website

apfpr.org.au

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Colorectal Surgery Craft Group

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SURGICAL OUTCOMES REGISTRIES



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— Head, Drug and Device Registries



Professor John McNeil AO

— Sir John Monash Distinguished Professor

— Head, Bariatric Surgery Registry

Australian Breast Device Registry (ABDR)

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Head, Australian Breast Device Registry

CLINICAL LEADS

Associate Professor

Gillian Farrell

Representing the Australian Society of Plastic Surgeons (ASPS)

Associate Professor Colin Moore

Representing the Australasian College of Cosmetic Surgery (ACCS)

Associate Professor

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Purpose/aims of the registry

The ABDR is a clinical quality registry designed to monitor the performance of breast implants and breast tissue expanders, and the quality and safety of breast device related surgery. It tracks the outcomes and quality of all breast device surgery performed across Australia. It will report progressively on the long term performance of implanted devices with the aim of improving patient safety.

Population captured

A pilot population-based registry was established in 2011. In 2015, the registry was rolled out to all breast device implanting sites nationwide. It will benchmark best surgical practice and report progressively on the long term performance of implanted breast devices with the aim to improve patient health outcomes by monitoring the safety and quality of breast implants.

Outcomes collected

- Time to revision
- Postoperative complications (e.g. capsular contracture, infection)
- Patient Reported Outcome Measures (at follow-up)
- Breast implant associated anaplastic large cell lymphoma

Year established

2015

Jurisdictions participating in 2019

All Australian jurisdictions.

Reports published/provided in 2019

2018 Annual Report

HREC Approval Number

HREC/15/Alfred/61

Number of data requests/ad hoc reports in 2019

Sites: 4; Surgeons: 5; Industry: 2; Researcher: 4

PROMs/PREMs collected

PROMs collected at 1, 2, 5 and 10 years after surgery

Funding source

Commonwealth Government (as represented by Department of Health)

Website

abdr.org.au

International Collaboration of Breast Registries (ICOBRA)

The International Collaboration of Breast Device Registry Activities (ICOBRA) commenced in 2013, and was developed to establish an internationally agreed and comparable minimum data set for breast device registries, comprising standardised and epidemiologically sound data that reflect global best practice in breast implant surgery. Contributing countries and organisations include national plastic and reconstructive surgery societies, national health services and national health regulatory agencies. Currently 20 countries are signatories.

At the heart of the ICOBRA concept is the core ethic and commitment to improving patient outcomes. The group met at the Monash campus in Prato, Italy in 2017. The Australian Breast Device Registry led two international panels to establish a global minimum data set, and global quality indicators to facilitate international benchmarking.

Work is being undertaken on an international breast device library, and towards harmonised annual reports.

Bariatric Surgery Registry (BSR)

Purpose/aims of the registry

The Bariatric Surgery Registry is a population-based observational quality improvement study of persons with obesity who have bariatric surgery. Within the remit of a clinical quality registry, its purpose is to gather and analyse information that is used to monitor and enhance the quality of care received by obese persons undergoing bariatric surgery in Australia and New Zealand. This includes the safety, efficacy and standards of bariatric surgery.

The Bariatric Surgery Registry does this by:

- recording the immediate safety of bariatric surgery in Australia and New Zealand by determining any events in the first 90 days post-surgery
- studying longitudinally the safety and efficacy of bariatric surgery in Australia and New Zealand
- continuous validation of data through thorough quality checks to ensure all data is accurate and true in its representation
- providing regular feedback to clinicians, allowing them to measure their performance against validated and quality checked reports

Population captured

The Registry collects data about persons with obesity undergoing bariatric surgery in private and public hospitals across Australia and New Zealand.

Outcomes collected

Clinical quality indicators (termed defined adverse events) within the 3 month period post operatively include:

- unplanned return to theatre
- unplanned ICU admission
- unplanned readmission to hospital
- mortality

The incidence of adverse events and deaths related to bariatric surgery are monitored for all participants. Clinical outcome measures in primary participants include:

- weight/BMI changes
- change in diabetes status
- change in diabetes treatment over time
- the need for revision surgery
- the effect on lifespan

The Registry aims to capture the clinical outcome measures on an annual basis for a period of up to 10 years for all primary participants.

Year established

2014

Jurisdictions participating in 2019

All States and Territories of Australia and New Zealand

Reports published/provided in 2019

- Hospital Group Reports (as at 31 December 2018)
- Seventh Annual Report of the Bariatric Surgery Registry (as at 30 June 2019)
- Semi-Annual Report (as at 31 December 2018)
- Individual Reports to Participating Surgeons (as at 30 September 2019)

HREC Approval Number

HREC/18/Alfred/75

Number of data requests/ad hoc reports in 2019

5

PROMs/PREMs collected

- Patient Reported Outcome Measures will commence as a standalone project in 2020 to determine an item bank specific for the bariatric field, in collaboration with both national and international obesity research groups
- Patient Reported Outcome Measures are projected to be implemented as a standard dataset routinely collected in the Registry in 2021

Funding source

- Commonwealth Government Department of Health
- Industry Partners – Applied Medical, AVANT, Gore, Johnson & Johnson, Medtronic

Website

monash.edu/medicine/sphpm/registries/bariatric

ACADEMIC LEAD

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Sir John Monash
Distinguished Professor
Head, Bariatric Surgery Registry

CLINICAL LEADS

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“At the end of 2019, the Bariatric Surgery Registry had successfully captured 89,756 procedures from a total of 82,910 participants across Australia and New Zealand. One of the key strengths of the Registry has been its ongoing surgeon and hospital engagement and relationship management, which has led to the participation of 216 surgeons from 134 hospitals having contributed to the study since it commenced.”

TRANSFUSION AND BLOOD DISEASES OUTCOMES REGISTRIES



Professor Erica Wood

— Head, Transfusion Research Unit



Associate Professor Zoe McQuilten

— Deputy Head, Transfusion Research Unit

Myeloma and Related Diseases Registry (MRDR)

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Purpose/aims of the registry

The aims of the MRDR are to:

- monitor trends in incidence and survival
- monitor access to care
- explore variation in practice, process and outcomes
- benchmark outcomes nationally and internationally
- explore the factors that influence outcomes including survival and quality of life
- be a resource for clinical trials and further research

The MRDR data on patterns of treatment and variation in patient outcomes allows evaluation of advances in therapy outside the setting of clinical trials, and will enable provision of the best possible care to people with these conditions.

Population captured

Patients with multiple myeloma, plasma cell leukaemia, monoclonal gammopathy of undetermined significance (MGUS) and plasmacytoma in Australia and New Zealand.

Outcomes collected

Demographics, diagnoses, clinical and laboratory results, therapy, complications of disease and therapy, clinical outcomes (including mortality, disease progression, best clinical response to therapy and quality of life).

Year established

2012

Jurisdictions participating in 2019

Australia and New Zealand.

Expansion to the Asia-Pacific region (see APAC MRDR).

Reports published/provided in 2019

Annual Report, 6 monthly data reports to sites, newsletter.

HREC Approval Number

HREC/16/Alfred/126; Local Reference: Project 23/17

Number of data requests/ad hoc reports in 2019

11 investigator-initiated requests, 2 reports for industry partners

PROMs/PREMs collected

EQ-5D-5L

Funding source

Industry partners, Myeloma Australia

Website

mrdr.net.au

“The MRDR achieved record recruitment in 2019 reaching more than 3,300 registrations overall, with 43 approved sites, and 410 patient samples accrued in the Myeloma 1000 Biobank.”



Asia Pacific Myeloma & Related Diseases Registry (APAC MRDR)

Purpose/aims of the registry

Asia Pacific Myeloma & Related Diseases Registry (APAC MRDR) aims to:

- monitor trends in practice, outcomes and survival
- understand access to care
- explore variation in practice, process and outcomes
- benchmark outcomes nationally and internationally
- explore factors that influence outcomes including survival and quality of life
- act as a resource for clinical trials and further research

Population captured

Patients ≥ 18 years in Asia-Pacific with a new diagnosis of myeloma, plasmacytoma, plasma cell leukaemia or monoclonal gammopathy of undetermined significance (MGUS).

Outcomes collected

Primary outcome:

- overall survival post-diagnosis in multiple myeloma which is assessed by review of hospital records and linkage with national death databases

Secondary outcome:

- progression-free post-diagnosis in multiple myeloma which is assessed by review of hospital records and linkage with national death databases

Year established

2018

Jurisdictions participating in 2019

Korea, Malaysia, Singapore and Taiwan

Reports published/provided in 2019

Hospital Data Reports – June 2019

Hospital Data Reports – December 2019

Annual Report to Funder – Year 2

HREC Approval Number

HREC/16/Alfred/126 (Local reference: 23/17)

Number of data requests/ad hoc reports in 2019

N/A

PROMs/PREMs collected

N/A

Funding source

Janssen-Cilag

Website

apacmrdr.org

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Myelodysplastic Syndromes Registry (MDSLink)

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Purpose/aims of the registry

The aims of the Registry are to:

- describe the demographic, clinical and diagnostic features of newly diagnosed MDS patients
- describe the therapeutic strategies utilised, including targeted and other pharmacological agents, and supportive care
- investigate any correlation between patient outcomes and prognostic, clinical and therapeutic factors, and explore factors that influence outcomes, including survival and QoL
- provide data on resource utilisation to inform health policy and planning
- monitor access to care
- benchmark outcomes nationally and internationally
- monitor trends in incidence and survival
- act as a resource for clinical trials

Population captured

Patients with a new diagnosis of MDS confirmed on bone marrow biopsy. This will include new diagnosis within 12 months prior to HREC approval at the site, or cause of death listed as MDS within 12 months prior to HREC approval at the site.

Outcomes collected

Health at diagnosis, demographic details. Laboratory and bone marrow biopsy results at diagnosis including cytogenetics and molecular studies if available.

Therapy decisions including pharmacological agents, transfusion practice and supportive therapy, and side effects of treatment. Outcomes (overall and progression free survival, duration of response and time to next treatment and quality of life measures – EORTC QLQ-C30, QUALMS), and long-term outcomes (through linkage with Cancer and Death Registries).

Year established

2018 (pilot project)

Jurisdictions participating in 2019

All Australian jurisdictions, commencing with a pilot in Victoria and collaboration from the South Australian MDS Registry (A/Prof Devendra Hiwase).

Reports published/provided in 2019

N/A

HREC Approval Number

HREC/18/MonH/341

Number of data requests/ad hoc reports in 2019

0

PROMs/PREMs collected

Nil

Funding source

Celgene and a bequest through Austin Health. Also in-kind support from Monash University's Department of Epidemiology and Preventive Medicine.

Website

monash.edu/medicine/sphpm/registries/mds

Lymphoma and Related Diseases Registry (LaRDR)

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Purpose/aims of the registry

The aims of the LaRDR are to:

- monitor access to care
- benchmark outcomes nationally and internationally
- explore variation in practice, process and outcome measures
- monitor trends in incidence and survival
- explore the factors that influence outcomes including survival and quality of life
- act as a resource for clinical trials

Population captured

Adult patients with a new diagnosis of non-Hodgkin lymphoma, Hodgkin lymphoma, chronic lymphocytic leukaemia and related diseases in Australia and New Zealand.

Outcomes collected

Demographics, diagnoses, health status at diagnosis, laboratory and imaging results at diagnosis, therapy, including pre-therapy benchmarking, chemotherapy, autologous and allogeneic stem cell transplantation, and maintenance and supportive therapies; outcomes (overall and progression-free survival, duration of response and time to next treatment and quality of life measures); long-term outcomes (through linkage with cancer and death registries).

The registry has expanded to include CLL-specific data.

Year established

2016

Jurisdictions participating in 2019

Australia

Reports published/provided in 2019

Initial data reports to sites and investigators.

HREC Approval Number

HREC/16/MonH/74

Number of data requests/ad hoc reports in 2019

17

PROMs/PREMs collected

Nil

Highlights in 2019

- posters presented at meetings at Lugano, Switzerland and Florida, USA
- paper presented at Blood, Perth, Australia

Funding source

Industry partners

Website

laradr.org

Australian New Zealand Massive Transfusion Registry (ANZ-MTR)

Purpose/aims of the registry

To collect and analyse data on transfusion practice and patient outcomes in the setting of critical bleeding and massive transfusion in Australia and New Zealand.

Population captured

All patients over the age of 18 years old who receive five or more units of red blood cells within any four-hour time period in any clinical setting.

Outcomes collected

Demographics, diagnoses, hospital admission details, transfusion information on all fresh blood products, plasma products and adjunctive therapies, as well as laboratory results for the patient's hospital admission. Patient outcomes include patient discharge and in-hospital mortality information. Long term outcomes are available through data linkages with death and other registries (i.e. death data).

Year established

2011

Jurisdictions participating in 2019

Australia and New Zealand.

Reports published/provided in 2019

Hospital Data Reports

ANZ-MTR Newsletter

HREC Approval Number

HREC/18/Alfred/85 (NMA sites only)

Number of data requests/ad hoc reports in 2019

0

PROMs/PREMs collected

N/A

Funding source

- Australian National Blood Authority
- Department of Health and Human Services, Victoria
- CSL Behring
- New Zealand Blood Service
- NHMRC partnership grant

Website

monash.edu/medicine/sphpm/units/transfusionresearch

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“The ANZ-MTR is excited to be approaching 10,000 cases in the registry.”

Aplastic Anaemia Registry (AAR)

Purpose/aims of the registry

The aims of the AAR are to:

- better define the incidence, natural history and clinical outcome of aplastic anaemia
- provide information on the range of therapeutic strategies being employed in the treatment of aplastic anaemia patients
- explore factors influencing clinical outcomes to better define optimal management of aplastic anaemia

Population captured

Adult and paediatric patients suffering from aplastic anaemia.

Outcomes collected

Demographics, diagnosis, laboratory and clinical results, complications of disease and therapy, clinical outcomes; if death, cause of death.

Year established

2013

Jurisdictions participating in 2019

Australia

Reports published/provided in 2019

N/A

HREC Approval Number

Monash University HREC, CF12/0423 – 2012000185

Number of data requests/ad hoc reports in 2019

0

PROMs/PREMs collected

Nil

Funding source

Maddie Riewoldt's Vision

Website

aaregistry.org.au

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Haemoglobinopathy Registry (HbR)

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CLINICAL LEAD

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Purpose/aims of the registry

The aims of the HbR are to:

- explore variation in practice, process and outcome measures
- explore the factors that influence outcomes including survival and quality of life
- benchmark outcomes nationally and internationally
- act as a resource for clinical trials
- inform and inspire future hypothesis-driven research in this area

Population captured

Patients with a diagnosis of sickle cell anaemia, the β -thalassaemia major and other haemoglobinopathies.

Outcomes collected

Demographics, diagnosis, laboratory, clinical and imaging results, complications of disease and therapy, and clinical outcomes.

Year established

2013

Jurisdictions participating in 2019

Victoria, New South Wales, South Australia, Western Australia, Queensland.

Reports published/provided in 2019

N/A

HREC Approval Number

HREC/16/MonH/156

Number of data requests/ad hoc reports in 2019

0

PROMs/PREMs collected

Nil

Funding source

Industry partners, Thalassaemia and Sickle Cell Australia, Thalassaemia Society of NSW.

Website

monash.edu/medicine/sphpm/registries/hbr

Neonatal Alloimmune Thrombocytopenia (NAIT) Registry

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CLINICAL LEADS

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REGISTRY CONTACT

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Purpose/aims of the registry

The aims of the Registry are to:

- better define the incidence, natural history and clinical outcome of NAIT
- provide information on the range of therapeutic strategies in the treatment of NAIT
- explore factors influencing clinical outcomes
- better define optimal management
- inform and inspire future hypothesis-driven research in this area

Population captured

Mothers with pregnancies affected by NAIT and babies suffering from consequences of NAIT.

Outcomes collected

Demographics, diagnoses, clinical and laboratory and imaging results, therapy, complications of disease and therapy, transfusion, and support including intravenous immunoglobulin and platelet transfusions, and clinical outcomes.

Year established

2009

Jurisdictions participating in 2019

All Australian jurisdictions

Reports published/provided in 2019

N/A

HREC Approval Number

HREC 09157B (NMA sites only)

Number of data requests/ad hoc reports in 2019

0

PROMs/PREMs collected

N/A

Highlight in 2019

International collaboration discussions in progress.

Funding source

Monash University's Department of Epidemiology and Preventive Medicine.

Website

monash.edu/medicine/sphpm/registries/naït

Thrombotic Thrombocytopenia Purpura (TTP)/Thrombotic Microangiopathies (TMA) Registry

Purpose/aims of the registry

The aims of the TTP/ TMA Registry are to:

- better define the incidence, natural history and clinical outcome of TTP and other TMAs
- provide information on the range of therapeutic strategies being employed in the treatment of TMA patients
- explore factors influencing clinical outcomes
- better define optimal management of TMA patients

Population captured

Data on all patients suffering from a TMA are collected and entered onto a central database.

Outcomes collected

Demographics, diagnoses, clinical and laboratory and imaging results, therapy, complications of disease and therapy, transfusion support requirements, and clinical outcomes.

Year established

2009

Jurisdictions participating in 2019

Australia and New Zealand

Reports published/provided in 2019

Annual Report

HREC Approval Number

Ethics approval received. CF08/1674 – 2008000856

There are lead HRECs in WA, NSW, Qld and NZ, and we are working to bring site approvals together under the NMA where possible.

Number of data requests/ad hoc reports in 2019

2

PROMs/PREMs collected

Nil

Funding source

Industry partners

Website

monash.edu/medicine/sphpm/registries/ttp

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Venous thromboembolism cohort study (VTE)

Purpose/aims of the registry

The aims of the VTE cohort study are to:

- better define the incidence, natural history and clinical outcome of VTE
- provide information on the range of therapeutic strategies being employed in the treatment of VTE patients
- explore factors influencing clinical outcomes
- better define optimal management of VTE patients
- inform and inspire future hypothesis driven research in this area

Population captured

Adult patients suffering from VTE at participating sites.

Outcomes collected

Demographics, diagnoses, therapeutics, outcome of VTE episode, complications of episode, complications of therapy, representations of VTE.

Year established

2012

Jurisdictions participating in 2019

Victoria

Reports published/provided in 2019

N/A

HREC Approval Number

Southern Health HREC Ref: 11129A

Number of data requests/ad hoc reports in 2019

0

PROMs/PREMs collected

Nil

Funding source

Monash University DEPM and ACBD through Department of Clinical Haematology, Central School, Alfred Hospital.

Website

monash.edu/medicine/sphpm/registries/vte

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TRAUMA AND EMERGENCY OUTCOMES REGISTRIES



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Professor Belinda Gabbe

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Associate Professor Janet Bray

— Chair, Aus-ROC Epistry Management Committee



Professor Carol Hodgson

— Deputy Director, Australian and New Zealand Intensive Care Research Centre

Australia New Zealand Trauma Registry (ATR)

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Purpose/aims of the registry

The ATR is a part of the Australian Trauma Quality Improvement Program (AusTQIP), which aims to develop and implement a national program to further improve the quality and safety of trauma care across Australia. Currently, 27 hospitals, designated as major trauma centres (MTCs), are part of the collaboration, and submit quarterly data to the registry. In 2018, New Zealand joined the collaboration, making the ATR a bi-national trauma registry. New Zealand submits severe injury data from seven major trauma centres.

Population captured

All trauma patients who present to one of the designated trauma centres with an injury severity score (ISS) greater than 12 or death after injury.

Outcomes collected

ATR data is defined by the Bi-National Trauma Minimum Dataset. The dataset includes but is not limited to the details of the injury event, pre-hospital observations, injuries sustained, treatments received, in-hospital observations and discharge status.

Year established

2012

Jurisdictions participating in 2019

Major trauma centres in all Australian states and territories (excluding Tasmania), and New Zealand.

Reports published/provided in 2019

Australia New Zealand Trauma Registry, Management of the Severely Injured in Australia, 1 July 2017 to 30 June 2018; Bi-annual road trauma data tables for the ATR, January to June 2019; July to December 2018.

HREC Approval Number

HREC/12/CIPHS/53

Number of data requests/ad hoc reports in 2019

4

PROMs/PREMs collected

Nil

Funding source

Federal Department of Health and Federal Bureau of Infrastructure, Transport and Regional Economics.

Website

atr.org.au

Victorian State Trauma Registry (VSTR)

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Purpose/aims of the registry

The VSTR provides a mechanism to monitor the system to inform service provision and development with an aim to reduce preventable deaths and permanent disability from major trauma. Changes to systems of care are monitored to ensure outcomes are improving including a reduction in deaths and disability over time.

Population captured

The registry collects and analyses patient information from 138 health services managing trauma patients across Victoria.

Outcomes collected

The VSTR collects routine in-hospital outcomes including mortality, length of stay, complications and discharge destination. In addition, the VSTR routinely follows up patients at six, 12 and 24 months after injury to collect health-related quality of life, function, disability, pain and return to work outcomes.

Year established

2001

Jurisdictions participating in 2019

138 participating hospitals in Victoria

Reports published/provided in 2019

Quarterly Reports

Annual Reports

HREC Approval Number

DHHS HREC: 11-14, MUHREC: 8226

Number of data requests/ad hoc reports in 2019

27

PROMs/PREMs collected

Education level, marital/relationship status, current residential status, return to work/study, pain (level, region and side), World Health Organization Disability Assessment Scale (WHODAS), Global outcome assessment, Extended Glasgow Outcome Scale (GOS-E), EuroQOL Group EQ-5D-5L (5 level), and EQ_VAS. Paediatric; Group EQ-5D-5L-Y (5 level youth) and King's Outcome Scale for Childhood Head Injury (KOSCHI).

Funding source

- Department of Health and Human Services
- Transport Accident Commission

Website

vstr.monash.org

Saudi Trauma Registry (STAR)

Purpose/aims of the registry

The Saudi Trauma Registry is a collaboration between the King Saud Medical City (KSMC) in Riyadh, Saudi Arabia and the National Trauma Research Institute at the Alfred Hospital. The objective has been to establish a national registry to examine epidemiology of major trauma, medical processes and treatments and risk adjusted outcomes, which will enable international comparisons. Currently the incidence of major trauma is much higher in Saudi Arabia than most developed countries and there is a national focus on improving injury prevention and outcomes. The STAR commenced data collection in 2017 and is a viable prototype for the pending national trauma registry.

Population captured

All patients that present to the KSMC as a result of injury that meet STAR inclusion criteria.

Outcomes collected

In-hospital outcomes of mortality; length of stay and hospital performance indicators. Risk adjusted benchmarking is enabled by comparison with The Alfred Health Trauma Registry (AHTR) data.

Year established

2017

Jurisdictions participating in 2019

King Saud Medical City, Riyadh, Saudi Arabia

Reports published/provided in 2019

Inaugural annual report planned for early 2020

HREC Approval Number

MUHREC 12430; Alfred HREC 436/19;
KSMC IRB H-01_R-053

Number of data requests/ad hoc reports in 2019

Managed locally at the KSMC

PROMs/PREMs collected

N/A

Funding source

Kingdom of Saudi Arabia Ministry of Health

Website

ntri.org.au/king-saud-medical-city-the-alfred-international-trauma-program-trauma-registry-development

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Victorian Orthopaedic Trauma Outcomes Registry (VOTOR)

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Purpose/aims of the registry

The VOTOR was established through a collaborative project involving Monash University (Department of Epidemiology and Preventive Medicine), the Alfred (Department of Trauma Surgery) and the Royal Melbourne Hospital (Department of Orthopaedics). The registry is a comprehensive database of orthopaedic injuries, treatment, complications and outcomes based on admissions to The Alfred, Royal Melbourne, University Hospital Geelong and Northern Hospitals.

The overarching aims are to:

- monitor orthopaedic injury management, treatment approaches and outcomes
- identify variations in orthopaedic clinical practice
- identify specific injuries, procedures and patient populations at risk of poor outcomes
- monitor the use of orthopaedic implants and their outcomes

Population captured

The Victorian Orthopaedic Trauma Outcomes Registry captures data about all patients with an emergency admission (> 24 hours) to the participating hospital with a new orthopaedic (bone) injury. Patients with a pathological fracture related to metastatic disease and/or, isolated soft tissue injuries and cases < 16 years of age are excluded. Eligible patients are identified by the discharge diagnosis through ICD-10-AM reports from the participating hospitals.

Outcomes collected

The VOTOR collects routine in-hospital outcomes including mortality, length of stay, complications and discharge destination. In addition, VOTOR routinely follows up patients at six, 12 and 24 months after injury to collect health-related quality of life, function, disability, pain and return to work outcomes.

Year established

2003

Jurisdictions participating in 2019

Victoria (Sentinel site registry – 4 sites)

Reports published/provided in 2019

VOTOR Annual Report 2018-2019

HREC Approval Number

DHHS 11/14, MUHREC: 8226

Number of data requests/ad hoc reports in 2019

8

PROMs/PREMs collected

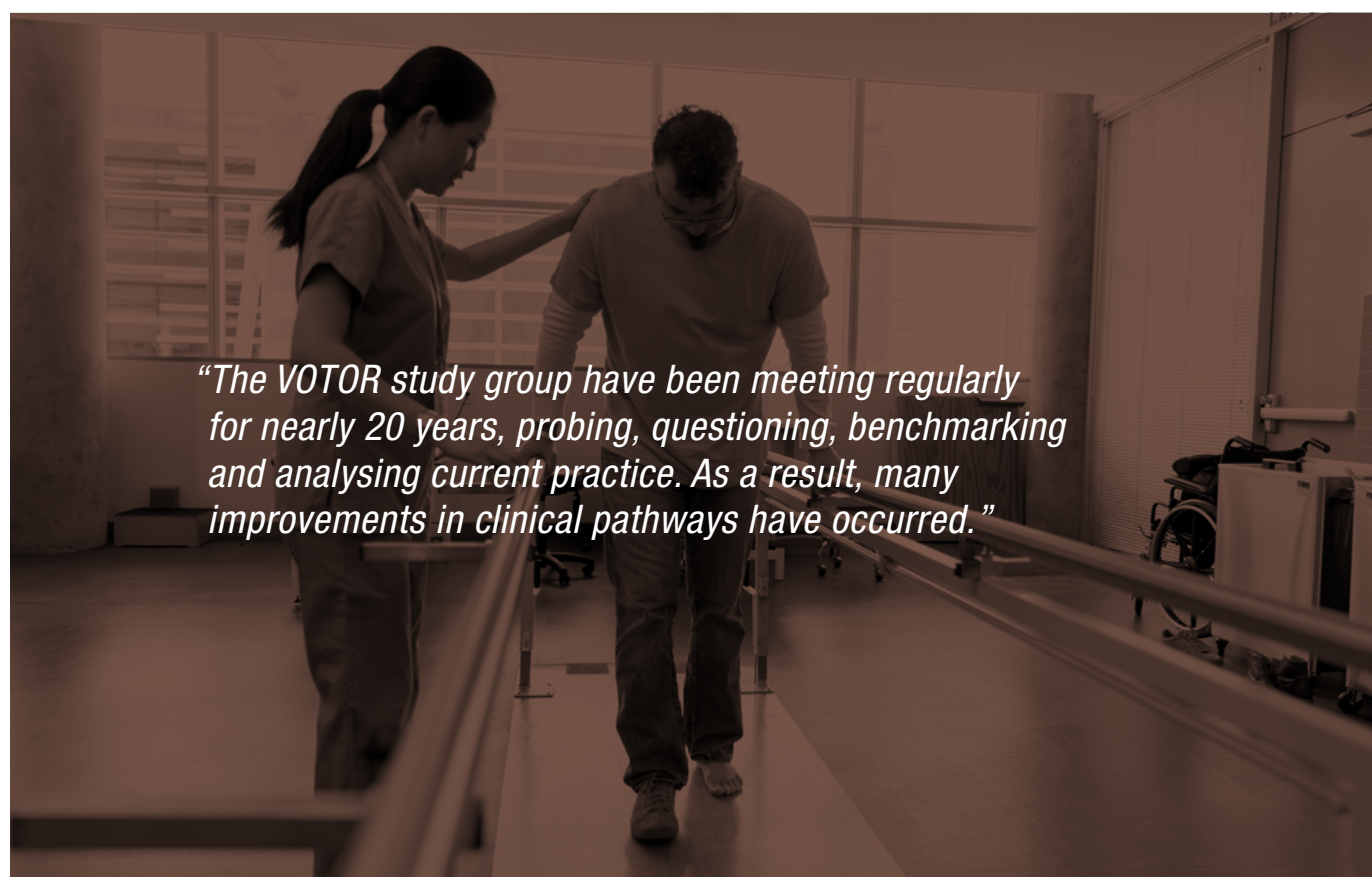
Education level, marital/relationship status, current residential status, return to work/study, pain (level, region and side), World Health Organization Disability Assessment Scale (WHODAS), Global Outcome Assessment, Extended Glasgow Outcome Scale (GOS-E), EuroQOL Group EQ-5D-5L (5 level), and EQ_VAS.

Funding source

Transport Accident Commission (TAC)

Website

votor.org.au



“The VOTOR study group have been meeting regularly for nearly 20 years, probing, questioning, benchmarking and analysing current practice. As a result, many improvements in clinical pathways have occurred.”

Burns Registry of Australia and New Zealand (BRANZ)

Purpose/aims of the registry

Significant burn injury is a distinct and important component of the overall burden of injury in Victoria and across Australia. The BRANZ provides valuable information on the incidence, aetiology, management, and outcomes of burn injury admitted to Australian and New Zealand specialist burn centres.

Population captured

The overall goal of the registry is to collect data on all burn patients admitted to a BRANZ burn unit who meet the inclusion criteria.

Outcomes collected

The BRANZ collects in-hospital outcomes including mortality, length of stay, complications, and discharge destination.

Year established

2009

Jurisdictions participating in 2019

Queensland, Victoria, Tasmania, Northern Territory, New South Wales and Australian Capital Territory, South Australia, Western Australia, and New Zealand.

Reports published/provided in 2019

2017/2018 Annual Report

HREC Approval Number

CF08/2431-2008001248

Number of data requests/ad hoc reports in 2019

14 data requests

PROMs/PREMs collected

Nil

Funding source

- Australian and New Zealand Burns Association
- Australian Commission on Safety and Quality in Health Care
- Helen Macpherson Smith Trust
- Julian Burton Burns Trust
- Thyne Reid Foundation
- Australasian Foundation for Plastic Surgery
- New Zealand Accident Compensation Corporation
- Clipsal by Schneider Electric National Community Grants Program
- HCF Research Foundation
- Individual Burn Units

Website

branz.org

ACADEMIC LEAD

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"The 2017/18 BRANZ Annual Report included a special focus on a growing social and clinical problem - burns in the elderly. They have relatively poor outcomes after burn injury, and decision making with respect to best management strategies can be difficult."

Aus-ROC Australian and New Zealand Out-of-Hospital Cardiac Arrest Epistry (Aus-ROC Epistry)

ACADEMIC LEAD

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Chair, Aus-ROC Epistry
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CLINICAL LEAD

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Purpose/aims of the registry

A key aim of the Australian Resuscitation Outcomes Consortium (Aus-ROC) CRE was to establish an Australian and New Zealand out-of-hospital cardiac arrest (OHCA) 'Epistry' (epidemiologic registry) to monitor and report on the population-based effects of changes in pre-hospital resuscitation policy and practice.

Specifically, the Aus-ROC Epistry was established with the aim of understanding regional, ambulance service and treatment factors associated with improved OHCA survival and outcomes. The scope of the Epistry will enable a range of important research questions to be answered, including: understanding regional variations in outcome; the impact of variations in the provision of treatment for OHCA between ambulance services; temporal changes in incidence and outcome; and the impact of changes in clinical guidelines and clinical trials.

Population captured

All out-of-hospital cardiac arrest patients in 6 states and territories in Australia (Victoria, South Australia, Western Australia, Queensland, Tasmania, and the Northern Territory) and all of New Zealand.

The total catchment population is approximately 20 million persons, representing 68% of the Australian population and 100% of the New Zealand population

Outcomes collected

Survival (prehospital, in-hospital or 30 days).

Year established

2015

Jurisdictions participating in 2019

Victoria (Ambulance Victoria), South Australia (SA Ambulance Service), Western Australia (St John Ambulance Western Australia), Queensland (Queensland Ambulance Service), Northern Territory (St John Northern Territory), Tasmania (Ambulance Tasmania) and New Zealand (St John New Zealand and Wellington Free Ambulance).

Reports published/provided in 2019

N/A

HREC Approval Number

MUHC 13933

Number of data requests/ad hoc reports in 2019

N/A

PROMs/PREMs collected

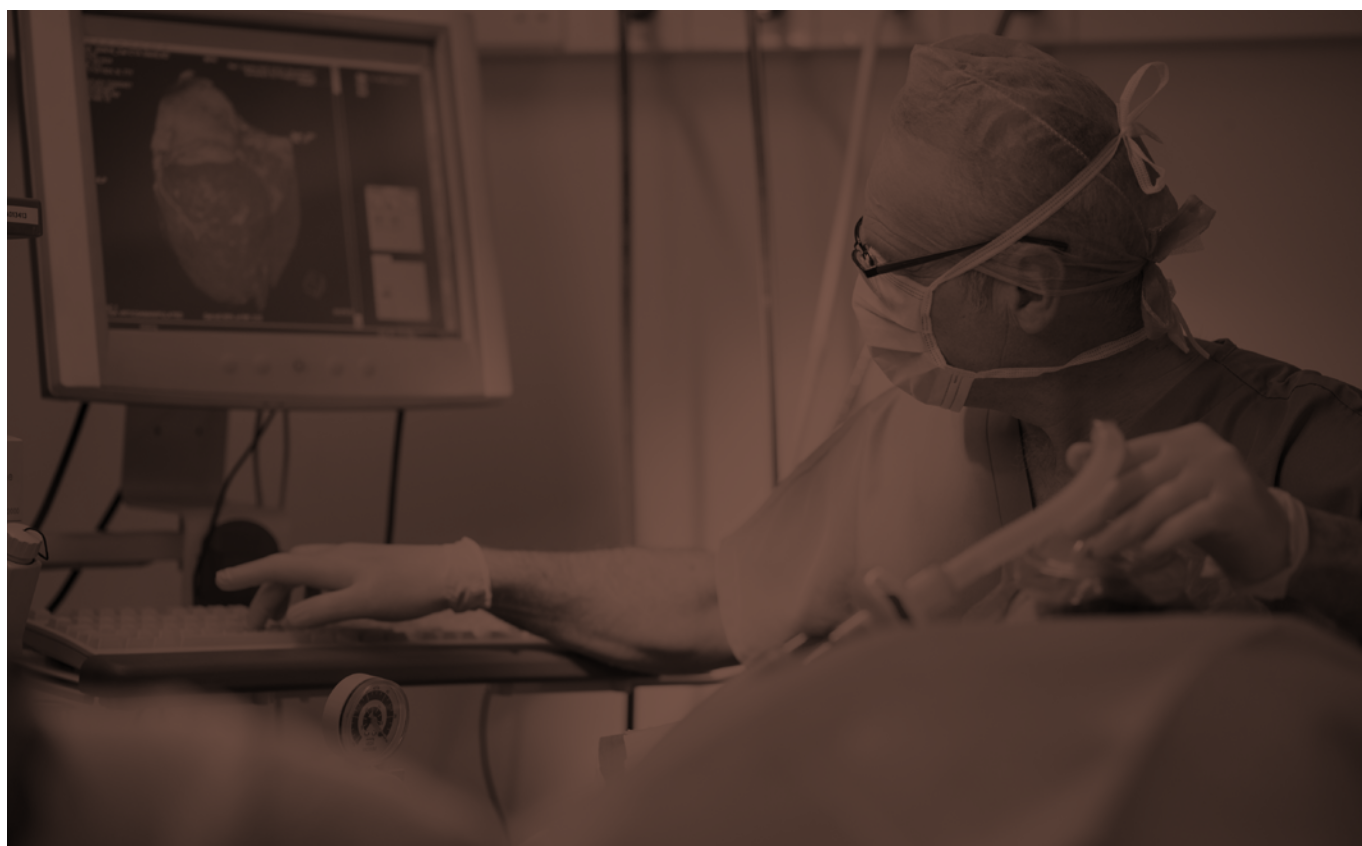
N/A

Funding source

NHMRC Centre of Research Excellence: Prehospital Emergency Care

Website

ausroc.org.au



EXCEL – The Australian and New Zealand extracorporeal membrane oxygenation registry

Purpose/aims of the registry

To generate a binational multidisciplinary network of integrated care for patients requiring ECMO to monitor long term outcomes and identify best practice. EXCEL uses the Theoretical Domains Framework to identify evidence-practice gaps and explore barriers and enablers to tailor implementation of evidence.

Population captured

Patients aged 18 years or older admitted to ICU who receive ECMO in Australia or New Zealand.

Outcomes collected

In-hospital outcomes:

- safety
- retrievals
- cannulation
- equipment and device utilisation
- mechanical ventilation and concomitant interventions
- survival
- healthcare utilisation

Six and 12 month outcomes:

- disability free survival
- health related quality of life
- anxiety and depression
- cognitive function
- return to work

Year established

2018

Jurisdictions participating in 2019

New South Wales, Queensland, Tasmania, South Australia, Victoria and Western Australia

Reports published/provided in 2019

EXCEL provides quarterly quality reports to all hospitals participating in EXCEL.

HREC Approval Number

Alfred Health 534/18

Number of data requests/ad hoc reports in 2019

3

PROMs/PREMs collected

Barthel Index; MoCA-Blind; EQ5D-5L; IADL; WHODAS 2.0 12L

Funding source

- Alfred Health
- National Health and Medical Research Council
- Heart Foundation
- Royal Prince Alfred Hospital
- St Vincent's Hospital, Sydney
- The Prince Charles Hospital
- University Hospital Geelong
- The International ECMO Network

Website

monash.edu/medicine/sphpm/anzicrc/research/excel

ACADEMIC LEAD

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