



**MONASH**  
University

MONASH  
PUBLIC HEALTH AND  
PREVENTIVE MEDICINE

# MONASH CLINICAL REGISTRIES 2020 REPORT



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I am delighted to share with you the Monash Clinical Registries Report for 2020.

2020 was an extremely challenging year across the University, as indeed it was internationally.

However, many of our clinical registries excelled and innovated to collect COVID-19 activity and outcomes, and to monitor longer term outcomes of their cohorts through future patient follow up. The importance of observational registries during the pandemic cannot be understated, particularly when health systems need to rapidly adapt to changing environments with limited ability to plan ahead. The Monash Clinical Registries' contribution to understanding how COVID has impacted clinical care and health service delivery across a range of acute and chronic conditions will be an enduring legacy of the pandemic.

A number of new clinical registries joined our program in 2020. These included the COVID-19-specific Short PeRiod IncideNce sTudy of severe Acute Respiratory Infection (SPRINT-SARI) in Australia; the Alfred Registry for Emergency Care (Alf-REC); the Melanoma Clinical Outcomes Registry (MelCOR); the National Cardiac Registry (NCR); and the Australian

Mesothelioma Registry (AMR), bringing the number of clinical registries in this report to **forty-three**.

The clinical registries in the 2020 report are aligned to the School's new Organisational Structure, which commenced in 2020. This includes the new clinical Divisions of Acute and Critical Care, Chronic Disease and Ageing, and Planetary Health, and the new methodological Division of Clinical and Health data Outcomes Innovation and Research (CHOIR), led by Professors Susannah Ahern and Belinda Gabbe. This new Division highlights the strategic importance of the clinical registry program to the School and the national leadership provided by this significant program.

I would like to recognise the enormous work undertaken by our registry academic and professional staff, as well as clinicians, researchers, consumer advocates, and consumers themselves for their tireless contribution to our registry program. I hope you are inspired by the breadth of endeavours to drive improvement in the quality of clinical care across our health system.

**Professor Sophia Zoungas**

# 2020: Monash Clinical Registries' Adaptability

## 2020 – A year like no other

2020 was a year like no other for south-east Australia. From the summer bushfires that ravaged the Victorian and NSW Alps, to the COVID-19 pandemic, which raged across the world, landing in Australia from February, and resulting in outbreaks and rolling lockdowns across the country. The impact on healthcare delivery was significant, nowhere more so than in Victoria.

Our clinical registries, which were designed to monitor the quality and outcomes of routine healthcare delivery, were however able to rapidly adapt to changing needs due to COVID. This included the pivoting of existing data collections towards COVID-related items – collecting data related to COVID exposure, infection, and outcomes. Equally importantly, our registries collected information on new models of care and expansion of previously under-utilised models of care including telehealth and home-based care.

Monash registries provided data about health service activities and outcomes that were requested and utilised by both State and Commonwealth governments. In this way, our registries provided an important and significant role in understanding the impact of the pandemic on routine healthcare delivery processes and outcomes in many areas including emergency and critical care, cardiac and surgical care, management of chronic medical conditions, and cancer. Our registries will continue to monitor the impact of the pandemic on longer term outcomes, using this information to inform clinical policy and practice for the future.



## Monash Clinical Registries and COVID-19

A number of Monash registries were at the forefront of COVID outcome monitoring. The Australian and New Zealand Intensive Care Research Collaboration (ANZICS-RC) in March 2020 pivoted an ICU microbiology data collection tool (ISACR) to focus on the collection of presentation, management and outcome information related to the majority of COVID presentations at ICUs across Australia (the SPRINT-SARI Registry). This information was rapidly translated into benchmarked reports to participating hospitals that profiled patient characteristics, treatments, and hospital-level outcomes, leading to rapid dissemination of practices that improved patient outcomes. SPRINT-SARI reports were provided not only to individual sites, but to the Commonwealth and Victorian COVID-19 expert advisory committees.

Similarly, the EXCEL Registry embedded data items related to COVID-19 that were harmonised with international registry data, and created a live map for clinicians to see where the use of extracorporeal membranous oxygenation (ECMO) was occurring for COVID-19, allowing collaboration, mentoring and guidance between sites. EXCEL also embedded two clinical trials into the registry comparing ECMO outcomes for patients with COVID-19 and those without.

There were concerns that the pandemic would result in delayed presentation of acute cardiac disease to Victorian health services, resulting in poorer outcomes for patients. The Victorian Cardiac Outcomes Registry (VCOR) tracked the impact of the pandemic on numbers and casemix of patients receiving percutaneous coronary interventions, and noted that while important process measures such as door to balloon time had increased, overall outcomes (eg, 30 day mortality) remained stable. Other cardiac registries, such as the Australian and New Zealand Society of Cardiothoracic Surgeons Database (ANZSCTS) monitored cardiac outcomes resulting from a shift in surgeries being undertaken in private hospitals so that public hospitals could predominantly manage COVID patients. Similarly, outcomes of high volume cancers were monitored during this time, with the Binational Colorectal Cancer Audit (BCCA) publishing on the effect of COVID-19 on colorectal cancer diagnosis and management.

For a number of Monash registries, the pandemic brought the world closer together. A number of new collaborations were formed, including with European countries (eg, the National Gynaecology Outcomes Registry), as well as broader international collaborations, eg, the COVID-19 Global Rheumatology Alliance. Existing activities such as the Australian & New Zealand and Asia-Pacific Myeloma and Related Diseases Registries and the Lymphoma and Related Diseases Registry all continued their substantial regional (APAC) and international scientific collaborations. Other international collaborations such as the Prostate Cancer TruNth data collection project was significantly impacted by delayed collection of international data, although ultimately incomplete data for the year was kept minimal. The Australian Cystic Fibrosis Data Registry (ACFDR) participated in an international collaboration of cystic fibrosis registries to produce a number of publications of pooled data regarding short and medium term outcomes of COVID-positive people with cystic fibrosis. The ACFDR also collected additional information regarding mode of care delivery, noting in its 2020 report that there was a substantial shift away from clinic based care (previously 80% of all visits) to telehealth care, comprising 44% of all visits in 2020.

For all Monash Registries, the 2020 lockdowns resulted in teams working from home for prolonged periods. Staff and call centres were relocated to home offices, and registries that utilised data collectors had to move to remove data collection where possible. Registries that were in the process of expanding often faced delays in ethics and governance approvals, while COVID-based research was (appropriately) prioritised. Regular face to face interaction and communication was difficult, and registries undertook training by webinars, videos and other creative approaches to keep sites engaged and participating where possible. Individual registries undertook specific risk management activities, such as the Prostate Cancer Outcomes Registry – Australia New Zealand (PCOR-ANZ) setting up a central risk register to monitor the impact of COVID and lockdowns in each jurisdiction to enable sharing across jurisdictional borders. Significantly, despite the pandemic, many registries reported similar volumes and participation compared with previous years, highlighting the adaptability of the registries and the value that they provide to clinicians across Australia.

See page 47 for Monash Clinical Registries publications in 2020 and early 2021 relating to Bushfires and the COVID-19 pandemic.

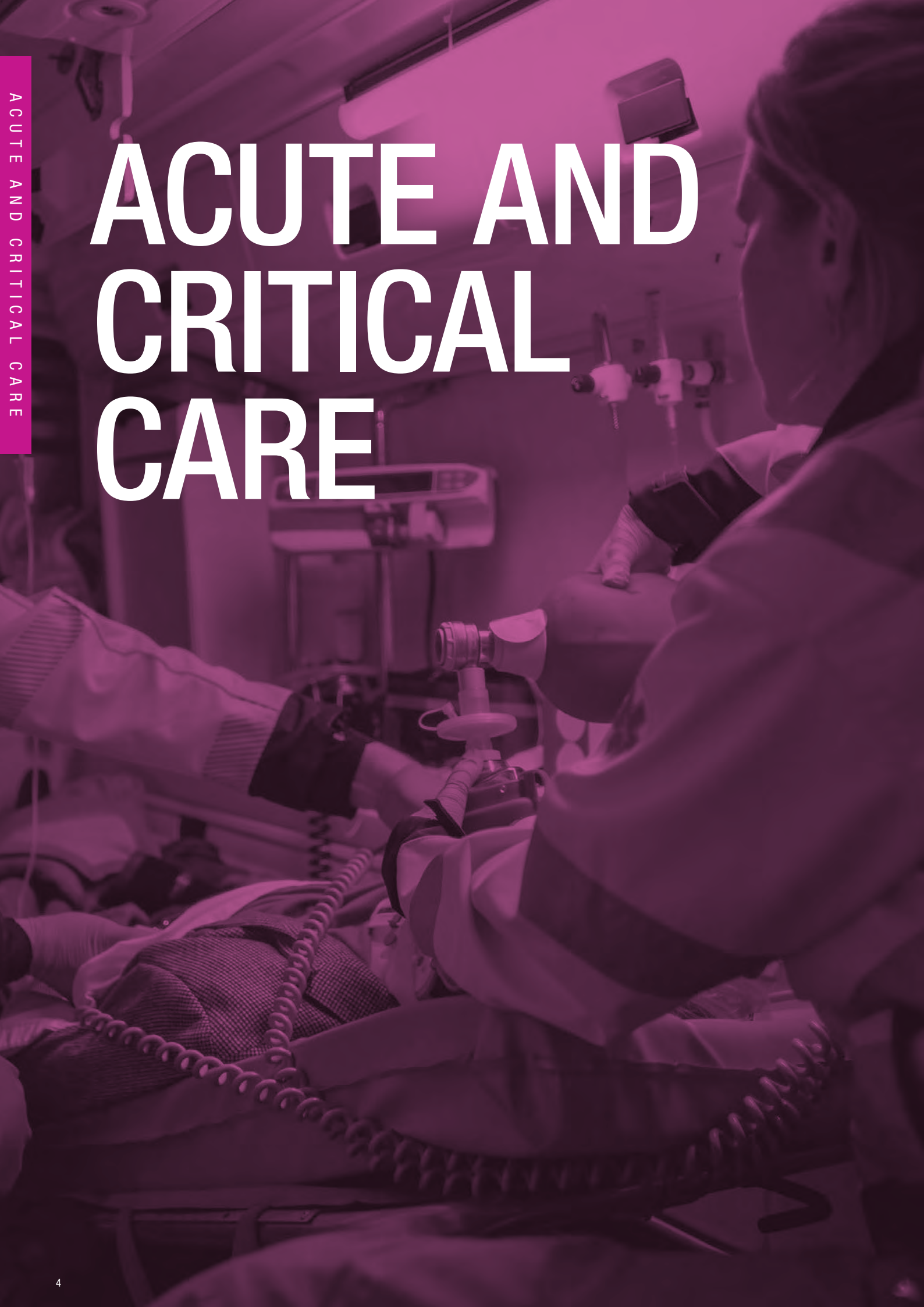


Professor Susannah Ahern  
Divisional Co-Head  
Clinical and Health data Outcomes Innovation and  
Research (CHOIR)



Professor Belinda Gabbe  
Divisional Co-Head  
Clinical and Health data Outcomes Innovation and  
Research (CHOIR)

# ACUTE AND CRITICAL CARE





## **Professor Carol Hodgson**

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



## **Professor Andrew Udy**

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

# EXCEL – The Australian and New Zealand extracorporeal membrane oxygenation registry

## ACADEMIC LEAD

### Professor Carol Hodgson

Deputy Director, Australian and New Zealand Intensive Care Research Centre

## CLINICAL LEAD

### Associate Professor

### Vincent Pellegrino

Senior Intensivist and Head, ECMO Clinical Service, Alfred Health

## REGISTRY CONTACT

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## 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 new and improved ECMO policy.

## Population captured

Any patient admitted to an adult hospital who undergoes ECMO intervention within Australia and New Zealand.

## Outcomes collected

In-hospital outcomes:

- safety event /adverse events
- retrieval status, timing, safety events and outcomes
- cannulation type, timing, operator
- equipment and device utilisation
- mechanical ventilation and concomitant
- interventions
- survival
- healthcare utilisation and costs

Six and 12 month outcomes:

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

## Year established

2018

## Jurisdictions participating in 2020

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

Currently working on ethics and governance requirements required and anticipate to have New Zealand activated by the end of 2021.

## Reports published/provided in 2020

EXCEL provides individual site reports every 6 months to all participating hospitals. We also generate and distribute an annual report capturing and pooling data from all sites, and a jurisdictional state-based report for each of the states and territories.

## HREC Approval Number

Alfred Health 534/18

## Number of data requests/ad hoc reports (received in 2020)

3 data requests, 2 ad hoc reports

## PROMs/PREMs collected

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

## Number of academic publications (published in 2020)

3

## 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](http://monash.edu/medicine/sphpm/anzicrc/research/excel)



# Short PeRiod IncideNce sTudy of severe Acute Respiratory Infection (SPRINT-SARI) in Australia

## Purpose/aims of the registry

SPRINT-SARI is an observational study in Severe Acute Respiratory Infection (SARI) more specifically COVID-19. SPRINT-SARI (Australia) collects COVID-19 data from the majority of Adult and Paediatric Australian ICUs. Seventy-nine ICUs are participating, with 64 sites currently contributing data to the registry. It supplies aggregate data to a number of Federal and State authorities to assist with modelling and resource allocation.

SPRINT-SARI (Australia) also adds to the global information on COVID-19 via links to The International Severe Acute Respiratory and emerging Infection Consortium (ISARIC, Oxford University – <https://isaric.org/>).

## Population captured

COVID-19 patients admitted to ICU

## Outcomes collected

- clinical severity
- hospital outcome
- length of stay in ICU
- length of stay in hospital
- human resource utilisation
- clinical resource utilisation

## Year established

2017

## Jurisdictions participating in 2020

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

## Reports published/provided in 2020

SPRINT-SARI (Australia) provides monthly reports to the Commonwealth Department of Health. It also makes these aggregate reports available to all Intensive Care clinicians to aid in COVID management and planning.

Aggregate data are used by AHPPC (Australian Health Protection Principal Committee) and The National COVID Incident Centre to inform Goal 9 and Goal 12 of The Australian National Disease Surveillance Plan for COVID-19.

## HREC Approval Number

Monash CF16/2333 - 2016001171

## Number of data requests/ad hoc reports (received in 2020)

SPRINT-SARI has received a number of requests for data use. These include Commonwealth and State Health Departments, and a number of modelling and research groups.

Each request is considered by the Management team prior to release of data.

## PROMs/PREMs collected

Nil

## Number of academic publications (published in 2020)

5

## Funding source

Commonwealth of Australia Department of Health

## Website

[medicine/sphpm/anzicrc/research](https://medicine/sphpm/anzicrc/research)

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## PRE-HOSPITAL, EMERGENCY AND TRAUMA RESEARCH

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— Professor of Emergency Medicine



**Professor Belinda Gabbe**

— Head, Pre-Hospital, Emergency and Trauma Research Unit



**Associate Professor Janet Bray**

— Chair, Aus-ROC Epistry Management Committee



**Associate Professor Gerard O'Reilly**

— Emergency Physician, Head of Global Programs, Alfred Emergency and Trauma Centre

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

## 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 attended by Ambulance Services in Australia and New Zealand. The total catchment population is approximately 29.4 million, representing 100% of the Australian population and 100% of the New Zealand population

## Outcomes collected

Any return of spontaneous circulation (ROSC); scene outcomes; ROSC on arrival at hospital; survival to hospital discharge/30 days.

**Year established**  
2015

## Jurisdictions participating in 2020

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), New South Wales (NSW Ambulance), Australian Capital Territory (ACT Ambulance Service) and New Zealand (St John New Zealand and Wellington Free Ambulance).

**Reports published/provided in 2020**  
N/A

**HREC Approval Number**  
MUHRC 13933

**Number of data requests/ad hoc reports (received in 2020)**  
N/A

**PROMs/PREMs collected**  
N/A

**Number of academic publications (published in 2020)**  
0

**Funding source**  
NHMRC Centre of Research Excellence: Prehospital Emergency Care

**Website**  
[ausroc.org.au](http://ausroc.org.au)

## ACADEMIC LEAD

**Associate Professor Janet Bray**  
Chair, Aus-ROC Epistry Management Committee

## CLINICAL LEAD

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## REGISTRY CONTACT

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# Alfred Registry for Emergency Care (Alf-REC)

## ACADEMIC LEAD

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## CLINICAL LEADS

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Adjunct, Alfred Hospital

### Professor Biswadev Mitra

National Trauma Research Institute

### Professor Peter Cameron

Emergency Medicine

### Associate Professor

#### de Villiers Smit

Director Alfred Emergency

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On behalf of the Alf-REC Team

## REGISTRY CONTACT

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## Purpose/aims of the registry

The purpose and aims of this registry are to monitor emergency care processes and outcomes.

There is a plan to, in partnership with the Australasian College for Emergency Medicine (ACEM), particularly its Emergency Department Epidemiology Network (EDEN), to develop a multinational (Australia and New Zealand), multi-site Registry for Emergency Care (REC), with support from Monash SPHPM emergency clinician researchers.

## Population captured

All Emergency Department presentations at Alfred Health Emergency.

## Outcomes collected

- Emergency Department length of stay
- Emergency Department disposition destination

## Year established

2020

## Jurisdictions participating in 2020

Alfred Health Emergency

## Reports published/provided in 2020

REC – Protocol

REC 1

## HREC Approval Number

282/20

## Number of data requests/ad hoc reports (received in 2020)

2

## PROMs/PREMs collected

Nil

## Number of academic publications (published in 2020)

2

## Funding source

Nil

## Website

[emergencyeducation.org.au/research/coved-project](http://emergencyeducation.org.au/research/coved-project)

## COVID-19 in ED (COVED)

### Purpose/aims of the registry

The aims of the Registry are to determine predictors and outcomes of COVID-19 for Emergency Department presentations.

### Population captured

Emergency Department presentations at 12 Emergency Departments across 4 Australian states.

### Outcomes collected

SARS-CoV-2 positive, survival to discharge.

### Year established

2020

### Jurisdictions participating in 2020

Alfred Health Emergency

### Reports published/provided in 2020

N/A

### HREC Approval Number

188/20

### Number of data requests/ad hoc reports (received in 2020)

5

### PROMs/PREMs collected

N/A

### Number of academic publications (published in 2020)

5

### Funding source

Nil

### Website

[emergencyeducation.org.au/research/coved-project/](http://emergencyeducation.org.au/research/coved-project/)

### ACADEMIC LEAD

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### CLINICAL LEADS

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National Trauma Research Institute

#### Professor Peter Cameron

Emergency Medicine

#### Associate Professor

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Director Alfred Emergency & Trauma Centre

On behalf of the Alf-REC Team

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## Australia New Zealand Trauma Registry (ATR)

### 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 and New Zealand. Currently, 27 Australian and 7 New Zealand hospitals, designated as major trauma centres (MTCs), are part of the collaboration, and submit quarterly data to the registry according to the binational minimum dataset. Considered a leading clinical quality registry, the ATR is able to provide risk adjusted outcomes and is currently recruiting sites in order to provide population-based data in the future.

### 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 Binational 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 2020

Major trauma centres in all Australian states and territories and New Zealand.

### Reports published/provided in 2020

Australia New Zealand Trauma Registry, Management of the Severely Injured in Australia, 1 July 2018 to 30 June 2019; Bi-annual road trauma data tables for the ATR, January to June 2020; July to December 2019.

### HREC Approval Number

HREC/12/CIPHS/53

### Number of data requests/ad hoc reports (received in 2020)

4

### PROMs/PREMs collected

Nil

### Number of academic publications (published in 2020)

Nil

### Funding source

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

### Website

[atr.org.au](http://atr.org.au)

### ACADEMIC LEAD

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### CLINICAL LEADS

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# Burns Registry of Australia and New Zealand (BRANZ)

## ACADEMIC LEAD

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## REGISTRY CONTACT

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## 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 2020

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

## Reports published/provided in 2020

Exploring burn injuries that occur during school holidays in Australian and New Zealand school-aged children

Annual Report 2018/2019 (features special focus on Australian bushfires)

## HREC Approval Number

CF08/2431-2008001248

## Number of data requests/ad hoc reports (received in 2020)

9

## PROMs/PREMs collected

Via a partnership between the Victorian Agency for Health Information and the BRANZ, a pilot is underway to collect long-term outcomes data in the Victorian burns population. Patients treated at the Burns Service at the Royal Children's Hospital and at the Victorian Adult Burns Service at The Alfred are being interviewed three, six and 12 months after their injury to understand how well they have recovered.

## Number of academic publications (published in 2020)

5

## Funding source

Australian and New Zealand Burn Association; Australian Commission on Safety and Quality in Healthcare; 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; Bethlehem Griffiths Research Foundation; Individual burn services

## Website

branz.org



## Saudi Trauma Registry (STAR)

### Purpose/aims of the registry

To establish a Trauma Registry as part of the King Saud Medical City – The Alfred international Trauma Program, that will become the prototype of a national Trauma Registry in the Kingdom of Saudi Arabia.

### Population captured

All patients that present to the King Saud Medical City as a result of injury, that meet Registry inclusion criteria.

### Outcomes collected

Hospital process indicators; discharge status; length of stay;

73 item minimum dataset

### Year established

2017

### Jurisdictions participating in 2020

Greater Riyadh

### Reports published/provided in 2020

2018-2019 annual report

### HREC Approval Number

The Alfred Hospital Research and Ethics Committee (Project ID: 436/19) and the KSMC Institutional Research Board (IRB Registration Number: H-01\_R-053)

### Number of data requests/ad hoc reports (received in 2020)

Unknown. Managed by on site team at the KSMC.

### PROMs/PREMs collected

None

### Number of academic publications (published in 2020)

1

### Funding source

Kingdom of Saudi Arabia (KSA) Ministry of Health (MOH)

### Website

N/A

### ACADEMIC LEAD

#### Professor Peter Cameron

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### CLINICAL LEAD

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### REGISTRY CONTACT

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## Victorian Orthopaedic Trauma Outcomes Registry (VOTOR)

### Purpose/aims of the registry

The VOTOR was established through a collaborative project involving Monash University (Epidemiology and Preventive Medicine), the Alfred (Trauma Surgery) and the Royal Melbourne Hospital (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 VOTOR 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 injury(ies) 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. 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 2020

Victoria (Sentinel site registry – 4 sites)

### Reports published/provided in 2020

VOTOR Annual Report 2019-2020

### HREC Approval Number

DHHS 11/14, MUHREC: 8226

### Number of data requests/ad hoc reports (received in 2020)

6

### 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.

### Number of academic publications (published in 2020)

8

### Funding source

Transport Accident Commission (TAC)

### Website

votor.org.au

### ACADEMIC LEAD

#### Professor Belinda Gabbe

Head, Pre-Hospital, Emergency and Trauma Research Unit

### CLINICAL LEAD

#### Professor Peter Cameron

Emergency Medicine

### REGISTRY CONTACT

#### Ms Melissa Hart

Project Manager

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*“VOTOR data has also been used increasingly for data linkage, including with the Australian Orthopaedic Association National Joint Replacement Registry, broadening the reach and scope in examining orthopaedic trauma related outcomes.”*

# Victorian State Trauma Registry (VSTR)

## ACADEMIC LEAD

### Professor Belinda Gabbe

Head, Pre-Hospital, Emergency and Trauma Research Unit

## CLINICAL LEAD

### Professor Peter Cameron

Emergency Medicine

## REGISTRY CONTACT

### Ms Mimi Morgan

Research Manager

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## Purpose/aims of the registry

We gather and interpret information about causes of traumatic injury and treatment from trauma services across Victoria. We work to improve quality of trauma care across the State, and to identify and reduce major risk factors for trauma in the community.

Our aim is to reduce preventable deaths and permanent disability from major trauma.

## Population captured

VSTR captures all major trauma patients in Victoria; broad-based inclusion criteria are used.

## Outcomes collected

6, 12 and 24 months

## Year established

2001

## Jurisdictions participating in 2020

138 Health Services across Victoria

## Reports published/provided in 2020

Annual Report 2018-2019

July-September 2019,

October-December 2019,

January-March 2020 and

April-June 2020 VSTR and TAC

Quarterly Reports

## HREC Approval Number

DHHS HREC: 114/10

## Number of data requests/ad hoc reports (received in 2020)

29

## 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.

## Number of academic publications (published in 2020)

20

## Funding source

- Department of Health and Human Services
- Transport Accident Commission

## Website

[vstorm.monash.org](http://vstorm.monash.org)





**Professor Erica Wood**

— Head, Transfusion Research Unit



**Associate Professor Zoe McQuilten**

— Deputy Head, Transfusion Research Unit

# Aplastic Anaemia and Other Bone Marrow Failure Syndromes Registry (AAR)

## ACADEMIC LEAD

### Professor Erica Wood

Head, Transfusion Research Unit

## CLINICAL LEADS

### Associate Professor

#### Zoe McQuilten

Deputy Head

Transfusion Research Unit

#### Dr Lucy Fox

Haematologist and Clinical Research Fellow, Transfusion Research Unit

#### Professor Frank Firkin

Haematologist, St Vincent's Hospital, Melbourne (Chair, Steering Committee)

## REGISTRY CONTACT

### Ms Vanessa Fox

Senior Research Officer  
1800 811 326  
aar@monash.edu

## Purpose/aims of the registry

The aims of the Aplastic Anaemia and Other Bone Marrow Failure Syndromes Registry (AAR) are to:

- better define the incidence of aplastic anaemia (AA) and related diseases such as Inherited Bone Marrow Failure Syndromes (IBMFS) in Australia
- provide information on the range of therapeutic strategies being employed in the treatment of AA and IBMFS patients, including immunosuppressive therapy and haematopoietic stem cell transplantation and supportive care
- document the specific genetic causes that underlie IBMFS and inherited predisposition to haematological malignancy in Australia
- explore factors influencing clinical outcomes
- investigate the relationship of PNH clones to progress of disease and response to therapy
- better define optimal management of AA and IBMFS patients
- inform and inspire future hypothesis-driven research in this area

## Population captured

Adult and paediatric patients suffering from aplastic anaemia and inherited bone marrow failure disorders.

## Outcomes collected

Diagnoses, laboratory and clinical results, clinical management including allogeneic haematopoietic stem cell transplantation, complications of disease and therapy, clinical outcomes; if death, cause of death.

## Year established

2013

## Jurisdictions participating in 2020

Australia

## Reports published/provided in 2020

Newsletter

## HREC Approval Number

Monash University HREC, CF12/0423 – 2012000185

## Number of data requests/ad hoc reports (received in 2020)

5 (clinical, research, community)

## PROMs/PREMs collected

Nil

## Number of academic publications (published in 2020)

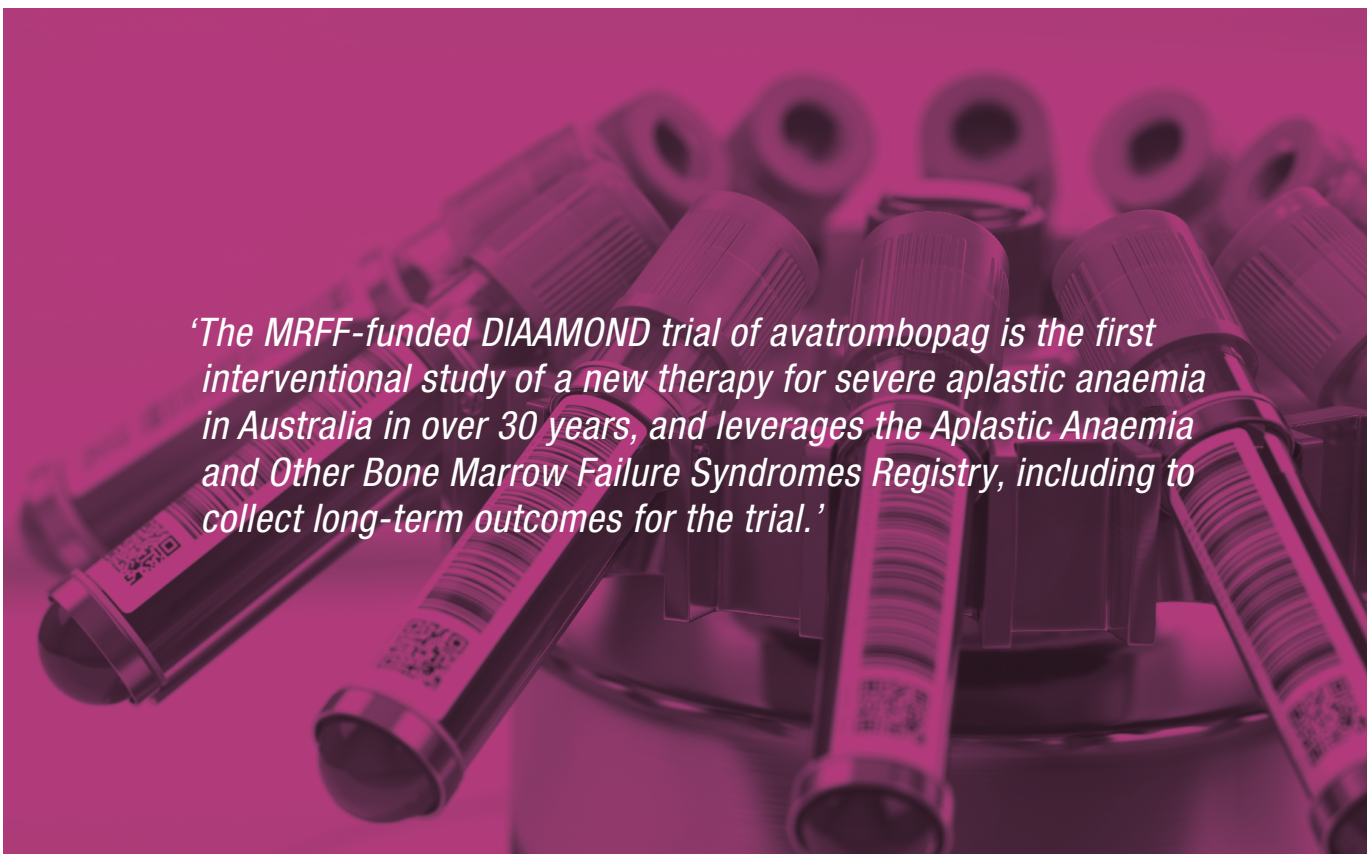
0

## Funding source

Maddie Riewoldt's Vision

## Website

aaregistry.org.au



*'The MRFF-funded DIAAMOND trial of avatrombopag is the first interventional study of a new therapy for severe aplastic anaemia in Australia in over 30 years, and leverages the Aplastic Anaemia and Other Bone Marrow Failure Syndromes Registry, including to collect long-term outcomes for the trial.'*

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

Also: diagnoses, laboratory and clinical results, clinical management including haematopoietic stem cell transplantation, complications of disease and therapy, clinical outcomes; if death, cause of death

### Year established

2018

### Jurisdictions participating in 2020

Korea, Malaysia, and Singapore

### Reports published/provided in 2020

- Bi-annual hospital data reports to eligible hospitals
- Annual Report to Funder
- Newsletters

### HREC Approval Number

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

### Number of data requests/ad hoc reports (received in 2020)

8 (clinical, research, industry, community)

### PROMs/PREMs collected

N/A

### Number of academic publications (published in 2020)

0

### Funding source

Janssen-Cilag

### Website

apacmrd.org

### ACADEMIC LEAD

**Professor Erica Wood**

Head, Transfusion Research Unit

### CLINICAL LEAD

**Professor Andrew Spencer**

Head, Malignant Haematology and Stem Cell Transplantation Service, Alfred Hospital (Chair, Steering Committee)

### REGISTRY CONTACT

**Ms Naomi Aoki**

Project Manager  
+61 3 9903 8270  
sphpm.apacmrd@monash.edu

## Australian and New Zealand Myeloma and Related Diseases Registry (MRDR)

### 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

Adult patients with multiple myeloma, plasma cell leukaemia, monoclonal gammopathy of undetermined significance (MGUS), amyloid light chain (AL) amyloidosis and plasmacytoma in Australia and New Zealand.

### Outcomes collected

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 2020

Australia and New Zealand.

### Reports published/provided in 2020

Annual report and newsletter  
6-monthly data reports to sites

### HREC Approval Number

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

### Number of data requests/ad hoc reports (received in 2020)

19 (clinical, research, industry, government, community)

### PROMs/PREMs collected

EQ-5D-5L

### Number of academic publications (published in 2020)

1

### Funding source

Industry partners, Myeloma Australia

### Website

mrd.net.au

### ACADEMIC LEAD

**Professor Erica Wood**

Head, Transfusion Research Unit

### CLINICAL LEADS

**Professor Andrew Spencer**

Head, Malignant Haematology and Stem Cell Transplantation Service, Alfred Hospital (Chair, Steering Committee)

**Associate Professor**

**Zoe McQuilten**

Deputy Head  
Transfusion Research Unit

### REGISTRY CONTACT

**Dr Elizabeth Moore**

Research Fellow  
1800 811 326  
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*“Despite COVID-19, strong accrual to the MRDR in 2020 continued, demonstrating the commitment of investigators and site staff to this important research.”*

# Australian and New Zealand Massive Transfusion Registry (ANZ-MTR)

## ACADEMIC LEAD

**Professor Erica Wood**  
Head, Transfusion Research Unit

## CLINICAL LEADS

**Professor James Isbister**  
Haematology (Chair,  
Steering Committee)

**Associate Professor  
Zoe McQuilten**  
Deputy Head  
Transfusion Research Unit

## REGISTRY CONTACTS

**Associate Professor  
Rosemary Sparrow**  
Senior Research Fellow

**Mrs Helen Haysom**  
Project Officer

1800 811 326  
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## 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 timeframe due to major haemorrhage in any clinical setting.

## Outcomes collected

Diagnoses, hospital admission details, laboratory results including transfusion information on all fresh blood products, plasma products and adjunctive therapies.

Patient outcomes include in-hospital mortality and status at patient discharge. Long term outcomes are available through data linkages with death and other registries.

**Year established**  
2011

**Jurisdictions participating in 2020**  
Australia and New Zealand.

## Reports published/provided in 2020

Hospital Data Reports  
Newsletter

**HREC Approval Number**  
HREC/18/Alfred/85 (NMA sites only)

**Number of data requests/ad hoc reports (received in 2020)**  
6 (clinical, research, government, industry, national blood service)

**PROMs/PREMs collected**  
N/A

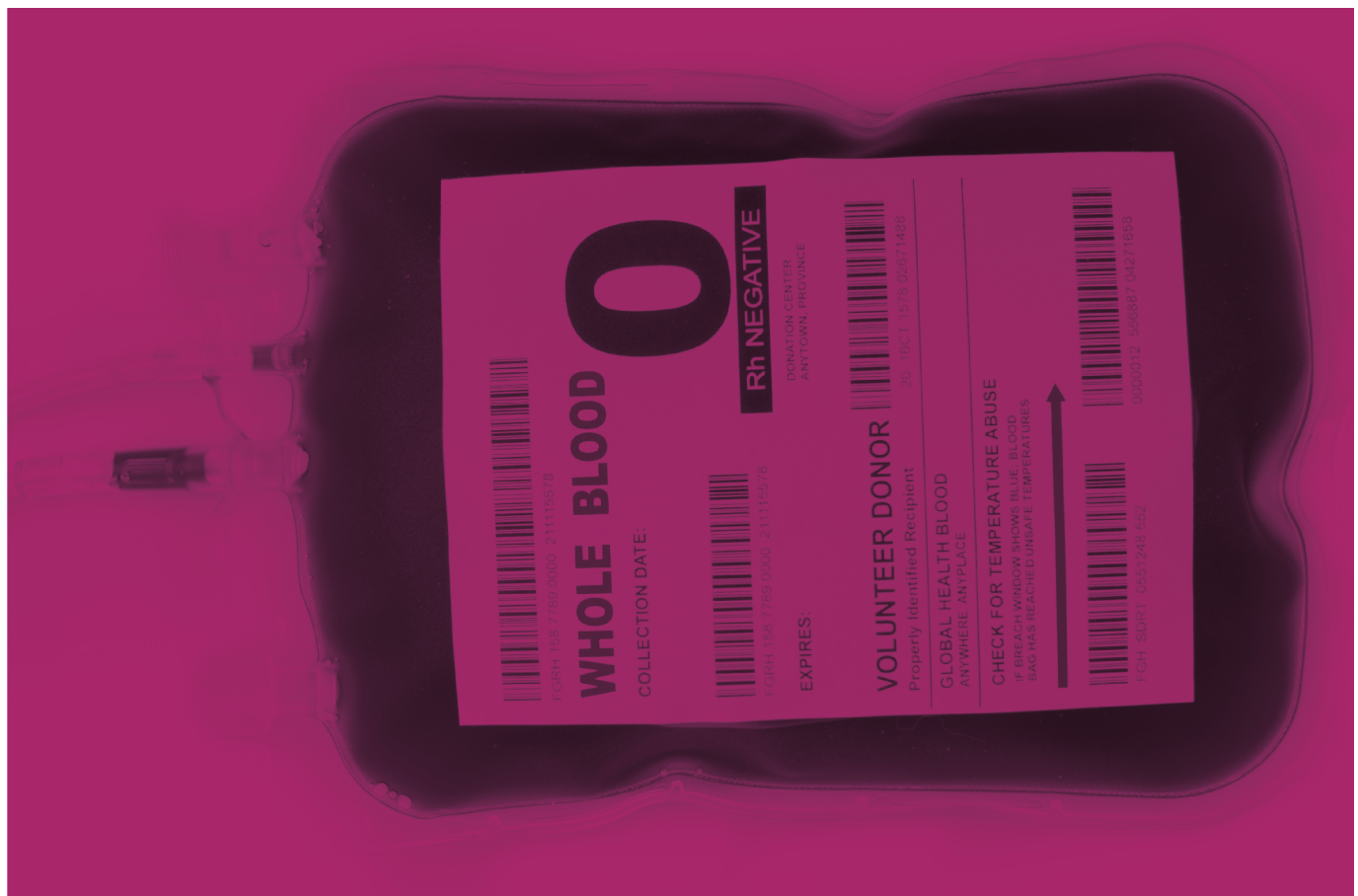
**Number of academic publications (published in 2020)**  
2

## Funding source

- Department of Health and Human Services, Victoria
- CSL Behring
- New Zealand Blood Service

## Website

monash.edu/medicine/sphpm/units/  
transfusionresearch



## Haemoglobinopathy Registry (HbR)

### 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

### Population captured

All patients with a diagnosis of sickle cell anaemia,  $\beta$ -thalassaemia major and other haemoglobinopathies.

### Outcomes collected

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

### Year established

2013

### Jurisdictions participating in 2020

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

### Reports published/provided in 2020

N/A

### HREC Approval Number

HREC/16/MonH/156

### Number of data requests/ad hoc reports (received in 2020)

5 (clinical, research, industry, government, community)

### PROMs/PREMs collected

Nil

### Number of academic publications (published in 2020)

Nil

### Funding source

Industry partners and (in past) Thalassaemia and Sickle Cell Australia, Thalassaemia Society of NSW.

### Website

monash.edu/medicine/sphpm/registries/hbr

### ACADEMIC LEAD

**Professor Erica Wood**

Head, Transfusion Research Unit

### CLINICAL LEAD

**Professor Joy Ho**

Haematology, Royal Prince Alfred Hospital, Sydney (Chair, Steering Committee)

### REGISTRY CONTACT

**Ms Melissa Chee**

Project Officer

**Mrs Helen Haysom**

Project Officer

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*“We still do not know how many Australians are living with thalassaemia and sickle cell disease. More data on these important conditions are required, in order to provide better health services and improve outcomes.”*

## Lymphoma and Related Diseases Registry (LaRDR)

### 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.

### Outcomes collected

Diagnoses, laboratory and imaging results, therapy decisions, including pre-therapy benchmarking, chemotherapy, autologous/allogeneic stem cell transplantation, maintenance and supportive therapies; outcomes (overall and progression-free survival, duration of response and time to next treatment and QoL measures [using the EQ-5D-5L]); and long-term outcomes (through linkage with cancer and death registries)

### Year established

2016

### Jurisdictions participating in 2020

Australia

### Reports published/provided in 2020

Annual report and newsletter  
Hospital Data Reports  
Industry reports x 5

### HREC Approval Number

HREC/16/MonH/74; Local Reference: Project 16213A

### Number of data requests/ad hoc reports (received in 2020)

12 (6 investigator-initiated requests, 6 for industry partners)

### PROMs/PREMs collected

N/A

### Number of academic publications (published in 2020)

1

### Funding source

Industry partners

### Website

lar.dr.org

### ACADEMIC LEAD

**Professor Erica Wood**

Head, Transfusion Research Unit

### CLINICAL LEADS

**Professor Stephen Opat**

Director, Clinical Haematology, Monash Health (Chair, Steering Committee)

**Associate Professor**

**Zoe McQuilten**

Deputy Head

Transfusion Research Unit

### REGISTRY CONTACT

**Ms Gayathri St George**

Senior Research Officer

1800 811 326

sphpm-lymphoma@monash.edu

# Neonatal (Feto-Maternal) Alloimmune Thrombocytopenia (NAIT) Registry

## ACADEMIC LEADS

### Professor Erica Wood

Head, Transfusion Research Unit

### Associate Professor

#### Zoe McQuilten

Deputy Head, Transfusion Research Unit

## CLINICAL LEADS

### Dr Stephen Cole

Obstetrics, Royal Women's Hospital (Chair, Steering Committee)

### Dr Gemma Crighton

Paediatric Haematology, Royal Children's Hospital

## REGISTRY CONTACT

### Mrs Helen Haysom

Project Officer  
1800 811 326  
med-nait@monash.edu

## 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

Diagnoses, clinical and laboratory and imaging results, therapy including intravenous immunoglobulin and platelet transfusions, complications of disease and therapy, and clinical outcomes.

## Year established

2009

## Jurisdictions participating in 2020

All Australian jurisdictions

## Reports published/provided in 2020

N/A

## HREC Approval Number

HREC 09157B (NMA sites only)

## Number of data requests/ad hoc reports (received in 2020)

3 (clinical, research, industry)

## PROMs/PREMs collected

N/A

## Number of academic publications (published in 2020)

0

## Funding source

N/A

## Website

monash.edu/medicine/sphpm/registries/nait

# The Myelodysplastic Syndromes Registry (MDSLink)

## ACADEMIC LEAD

### Professor Erica Wood

Head, Transfusion Research Unit

## CLINICAL LEAD

### Associate Professor

#### Melita Kenealy

Consultant Haematologist, Cabrini Hospital (Chair, Steering Committee)

## REGISTRY CONTACT

### Mr Neil Waters

Senior Projects Manager  
1800 811 326  
sphpm-mdsregistry@monash.edu

## Purpose/aims of the registry

The aims of the MDSLink are to:

- describe the demographic, clinical and diagnostic features of newly diagnosed patients with myelodysplastic syndromes (MDS)
- 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

Adult patients with a new diagnosis of MDS confirmed on bone marrow biopsy in Australia.

## Outcomes collected

Diagnoses, 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 2020

Australia

## Reports published/provided in 2020

Annual report

## HREC Approval Number

HREC/18/MonH/341; Local Reference: 18-0000-231A

## Number of data requests/ad hoc reports (received in 2020)

3 (clinical, research, community)

## PROMs/PREMs collected

EORTC QLQ-C30 and QUALMS

## Number of academic publications (published in 2020)

0

## Funding source

Bristol-Myers Squibb; patient bequest Austin Hospital

## Website

monash.edu/medicine/sphpm/registries/mdslink

## Thrombotic Microangiopathies (TMA) Registry

### Purpose/aims of the registry

The aims of the TMA Registry are to:

- determine the incidence, natural history, specific clinical characteristics, and clinical outcomes of patients with TMAs, particularly TTP, HUS and aHUS
- provide information on the range of therapies employed in the treatment of TMA patients
- explore factors influencing clinical outcomes
- help define optimal management of patients with TTP and HUS
- inform and inspire future hypothesis-driven research

### Population captured

All patients suffering from a TMA, with a focus on thrombotic thrombocytopenic purpura and atypical haemolytic uraemic syndrome.

### Outcomes collected

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

### Year established

2009

### Jurisdictions participating in 2020

Australia and New Zealand

### Reports published/provided in 2020

Annual Report, newsletter

### HREC Approval Number

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 (received in 2020)

3 (clinical, research, industry)

### PROMs/PREMs collected

Nil

### Number of academic publications (published in 2020)

0

### Funding source

Industry partners

### Website

monash.edu/medicine/sphpm/tma

### ACADEMIC LEAD

**Professor Erica Wood**

Head, Transfusion Research Unit

### CLINICAL LEAD

**Associate Professor Solomon (Shlomo) Cohney**

Nephrologist, Western Health  
(Chair, Steering Committee)

### REGISTRY CONTACT

**Mrs Helen Haysom**

TMA Registry Coordinator

1800 811 326

tmaregistry@monash.edu

## 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

Diagnoses, therapeutics, outcomes of VTE, complications of disease and therapy including re-presentations.

### Year established

2012

### Jurisdictions participating in 2020

Victoria

### Reports published/provided in 2020

N/A

### HREC Approval Number

Southern Health HREC Ref: 11129A

### Number of data requests/ad hoc reports (received in 2020)

2 (clinical, research)

### PROMs/PREMs collected

Nil

### Number of academic publications (published in 2020)

0

### Funding source

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

### Website

monash.edu/medicine/sphpm/registries/vte

### ACADEMIC LEAD

**Professor Erica Wood**

Head, Transfusion Research Unit

### CLINICAL LEAD

**Professor Huyen Tran**

Haematology, Alfred Health  
(Chair, Steering Committee)

### REGISTRY CONTACT

**Mr Neil Waters**

Senior Projects Manager

1800 811 326

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# CHRONIC DISEASE AND AGEING





## Professor Rachelle Buchbinder

— Director, Monash Department of Clinical Epidemiology, Cabrini Institute

## 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 2020

Australia

### Reports published/provided in 2020

Annual – personalised for Rheumatologists

### HREC Approval Number

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

### Number of data requests/ad hoc reports (received in 2020)

4

### 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 Live Inventory (for JIA), the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) (for AS)).

PREMs: Nil

### Number of academic publications (published in 2020)

2

### 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

### ACADEMIC LEAD

#### Professor Rachelle Buchbinder

Director, Monash Department of Clinical Epidemiology, Cabrini Institute

### CLINICAL LEADS

#### Professor Rachelle Buchbinder

Rheumatology

#### Professor Lyn March

Rheumatology

#### Professor Marissa Lassere

Rheumatology

#### Professor Catherine Hill

Rheumatology

### REGISTRY CONTACT

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arad@monash.edu



**Professor John Zalberg**

— Head, Cancer Research Program



**Dr Nathan Papa**

— Head, Prostate Cancer Registry Research

# 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. In 2021, the registry will be expanded 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. Thirteen clinical indicators have been developed for monitoring outcomes via benchmarked reports.

## Year established

2017

## Jurisdictions participating in 2020

Victoria, New South Wales, South Australia and Queensland

## Reports published/provided in 2020

ANZTCR Annual Report 2019

## HREC Approval Number

HREC/16/Alfred/61

## Number of data requests/ad hoc reports (received in 2020)

0

## PROMs/PREMs collected

In 2020, work towards the collection of PROMs and PREMs commenced with a systematic review and qualitative study to identify the most appropriate measures. In 2021, the processes to administer these measures through the registry will be piloted.

## Number of academic publications (published in 2020)

0

## Funding source

Australian and New Zealand Endocrine Surgeons, Medtronic, Alfred Foundation

## Website

[anztcr.org.au](http://anztcr.org.au)

## ACADEMIC LEADS

### Professor Jeremy Millar

Radiation Oncology

### Professor John Zalberg

Head, Cancer Research Program

## CLINICAL LEAD

### Professor Jonathan Serpell

Endocrine Surgeon

## REGISTRY CONTACT

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Registry Data Manager

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[anztcr@monash.edu](mailto:anztcr@monash.edu)

# Binational Colorectal Cancer Audit (BCCA)

## ACADEMIC LEAD

### Professor John Zalberg

Head, Cancer Research Program

## CLINICAL LEAD

### Dr Philip Smart

Colorectal Surgeon

## REGISTRY CONTACT

### Dr Hayat Dagher

Project Manager  
+61 3 9853 8013  
bccca@cssanz.org

## 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. It was started as a clinical surgeon-led surgical audit applicable to all surgeons who perform colorectal cancer surgery.

BCCA data are used for clinical audit of the surgical practices of Australian and New Zealand surgeons for the purpose of quality assurance. The audit also contributes 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 2020

All Australian States and Territories as well as New Zealand.

## Reports published/provided in 2020

The 2020 Binational Colorectal Cancer Audit Report and the 2020 Clinical Quality Reports to eligible sites.

## HREC Approval Number

Multiple HRECs including NMA

## Number of data requests/ad hoc reports (received in 2020)

8 data requests

## PROMs/PREMs collected

Not at present

## Number of academic publications (published in 2020)

10

## Funding source

Colorectal Surgical Society of Australia and New Zealand (CSSANZ) Members' annual subscription fee contribution; CSSANZ support; Royal Australian College of Surgeons (RACS); Epworth Health; and Medtronics for education and reporting initiatives.

## Website

bowelcanceraudit.com

*“BCCA investigators published “The short to medium term benefits of the Australian colorectal cancer screening program” which attracted media coverage for its promotion of the benefits of bowel cancer screening.”*

# MelCOR – Melanoma Clinical Outcomes Registry

## Purpose/aims of the registry

MelCOR is an independent Australian clinical quality registry that plans to collect information from various channels to consolidate information regarding the early treatment of melanoma into a central repository for all of Australia. The aim of the registry is to identify variation in care, and to produce benchmarked reports against agreed clinical quality indicators to drive improvements in patient outcomes

## Population captured

MelCOR has the goal of capturing all melanoma cases diagnosed in Queensland and Victoria for patients over the age of 18.

## Outcomes collected

During 2020, MelCOR was in an establishment phase, focusing on how data is captured.

## Year established

2020

## Jurisdictions participating in 2020

Queensland and Victoria

## Reports published/provided in 2020

0

## HREC Approval Number

The Alfred HREC 58280 (Local Reference: Project 127/20)

## Number of data requests/ad hoc reports (received in 2020)

0

## PROMs/PREMs collected

PROMs/PREMs are currently outside the scope of the MelCOR project.

## Number of academic publications (published in 2020)

0

## Funding source

MelCOR is funded by public fundraising efforts (Melanoma Marches) organised by the Melanoma Institute Australia.

## Website

[melcor.org.au](http://melcor.org.au)

## ACADEMIC LEAD

**Professor John Zalcberg**

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## CLINICAL LEAD

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**Victoria Mar**

Director, Victorian  
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# National Gynae-Oncology Registry (NGOR)

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Head, Cancer Research Program

## CLINICAL LEAD

**Associate Professor**

**Robert Rome**

Gynaecological Oncologist

Ovarian, Tubal and Peritoneal

Working Group Chair

## REGISTRY CONTACT

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Registry Coordinator

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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

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 vulvar cancer and rare tumour modules are in development phase.

## Outcomes collected

The NGOR collects information relating to patient care pathways. For the ovarian cancer 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 2020

New South Wales, Tasmania, Victoria and Western Australia. The registry is currently working towards capturing sites in Queensland.

## Reports published/provided in 2020

1

## HREC Approval Number

HREC/17/MonH/198

## Number of data requests/ad hoc reports (received in 2020)

N/A due to registry immaturity

## PROMs/PREMs collected

A sub-study is underway to collect PROMs and PREMs within the NGOR.

## Number of academic publications (published in 2020)

1

## Funding source

- Australian Society of Gynaecologic Oncologists (ASGO)
- CASS ('Contributing to Australian Scholarship and Science') Foundation
- Medical Research Future Fund (MRFF)
- Ovarian Cancer Australia
- The Epworth Medical Foundation

## Website

ngor.org.au

*“The NGOR was one of eight research projects to be awarded MRFF funding to support ovarian cancer research.”*

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

### 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 2020

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

### Reports published/provided in 2020

PCOR-ANZ 2019 Annual Report

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

### HREC Approval Number

MUHREC/21692

### Number of data requests/ad hoc reports (received in 2020)

7

### PROMs/PREMs collected

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

### Number of academic publications (published in 2020)

0

### Funding source

Movember Foundation

### Website

prostatecancerregistry.org

### ACADEMIC LEAD

**Dr Nathan Papa**

Head, Prostate Cancer Registry Research

### CLINICAL LEADS

**Professor Jeremy Millar**

Radiation Oncology

**Adjunct Professor**

**Peter Heathcote**

Urology

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### REGISTRY CONTACT

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*“In 2020, 583 reports were distributed to contributing clinicians and institutes. We also commenced a pilot program trialling a mobile application to provide urologists close to real-time feedback on quality outcomes.”*

## Prostate Cancer Outcomes Registry — Victoria (PCOR-VIC)

### 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 90 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 2020

Victoria

### Reports published/provided in 2020

Bi-annual clinician and hospital benchmarking reports.

### HREC Approval Number

HREC/16/Alfred/98

### Number of data requests/ad hoc reports (received in 2020)

11

### PROMs/PREMs collected

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

### Number of academic publications (published in 2020)

2

### Funding source

- Movember Foundation

### Website

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

### ACADEMIC LEAD

**Dr Nathan Papa**

Head, Prostate Cancer Registry Research

### CLINICAL LEAD

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Radiation Oncology

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# TrueNTH Global Registry

## ACADEMIC LEAD

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Registry Research

## CLINICAL LEAD

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Department of Urology, UCLA

## REGISTRY CONTACT

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## Purpose/aims of the registry

The TrueNTH registry aims to significantly improve the physical health and quality of life of men treated for prostate cancer.

## Population captured

Men diagnosed with localised prostate cancer.

## Outcomes collected

- treatment outcomes data including positive margin rate post prostatectomy, PSA at 12 months post diagnosis/treatment and death
- patient-reported quality of life at 12 months post diagnosis/treatment

## Year established

2017

## Jurisdictions participating in 2020

13 countries

## Reports published/provided in 2020

We delivered biannual benchmarked quality reports to 181 participating centres.

## HREC Approval Number

Multiple HREC/IRB around the world.

## Number of data requests/ad hoc reports (received in 2020)

4 project-wide analyses

## PROMs/PREMs collected

Expanded Prostate Cancer Index Composite-26 Short Form (EPIC-26); The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Prostate Cancer Module (EORTC QLQ PC-25); Utilisation of Sexual Medications/ Devices questionnaire

## Number of academic publications (published in 2020)

0

## Funding source

Movember

## Website

tngr.movemberhealth.org

# Upper Gastrointestinal Cancer Registry (UGICR)

## ACADEMIC LEAD

### Professor John Zalberg

Head, Cancer Research Program

## CLINICAL LEADS

### Professor Wendy Brown

Oesophagogastric Cancer  
Module

### Dr Dan Croagh

Pancreas Cancer Module

### Associate Professor

### Charles Pilgrim

Biliary Cancer Module

### Professor Stuart Roberts

Primary Liver Cancer Module

## REGISTRY CONTACT

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## Purpose/aims of the registry

The Upper Gastrointestinal Cancer Registry (UGICR) is a clinical quality registry that aims to improve the outcomes and quality of care for patients recently diagnosed with cancers arising in the oesophagus; stomach; pancreas, liver; and biliary system.

## Population captured

All people newly diagnosed with oesophageal, gastric, pancreatic, primary liver (hepatocellular carcinoma) and biliary system cancer, who have been diagnosed or received assessment, treatment of care at a participating hospital or health service.

## Outcomes collected

The UGICR collects demographic, contact, diagnostic, treatment, pathology, imaging and outcome data from medical records.

## Year established

2016

## Jurisdictions participating in 2020

Victoria, New South Wales, Australian Capital Territory

## Reports published/provided in 2020

N/A

## HREC Approval Number

HREC/15/MonH/134

## Number of data requests/ad hoc reports (received in 2020)

3

## PROMs/PREMs collected

The collection of patient-reported outcomes (PROs) and experiences (PREs) is currently being piloted in the pancreatic module of the UGICR.

## Number of academic publications (published in 2020)

3

## Funding source

NHMRC project grant; Avner Foundation; Epworth Foundation; Monash Partners Comprehensive Cancer Centre; PAN CARE; BMS; Viatrix; Eisai; AstraZeneca; Ipsen.

## Website

ugicr.org.au



# Victorian Lung Cancer Registry (VLCR)

## Purpose/aims of the registry

The VLCR is a clinical quality registry that aims to measure and benchmark quality of care for patients newly diagnosed with lung cancer 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 records all newly diagnosed primary lung cancer cases at participating sites in Victoria. The VLCR participating sites include over 85% of all hospitals in Victoria currently treating 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 2020

The VLCR has 22 sites across metropolitan and regional Victoria, including public and private institutions.

## Reports published/provided in 2020

2019 Quality Indicator Report

## HREC Approval Number

HREC/16/Alfred/84

## Number of data requests/ad hoc reports (received in 2020)

Multiple site requests for their own data  
5 additional research related data requests have been approved

## PROMs/PREMs collected

PROMs and PREMs are being piloted as part of a VLCR sub-study (Value-based Healthcare) at diagnosis and 3-monthly after this for 12-months.

## Number of academic publications (published in 2020)

5

## Funding source

- MRFF
- DHHS
- Pfizer
- MSD
- IQVIA

## Website

[vlcr.org.au](http://vlcr.org.au)

## ACADEMIC LEAD

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## **Professor Danny Liew**

— Co-Director, Monash, Centre of Cardiovascular Research and Education in Therapeutics



## **Professor Chris Reid**

— Co-Director, Monash, Centre of Cardiovascular Research and Education in Therapeutics

# 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 across Australia and New Zealand through a peer reviewed quality assurance program, the production of comprehensive annual reports and an active research program.

## Population captured

The ANZSCTS Database aims to capture all adult cardiac surgical operations in Australia and New Zealand. In 2020, 47 hospitals contributed data to the Program including all public hospitals (that perform cardiac surgery) in Australia.

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 2020

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

## Reports published/provided in 2020

National Annual Report 2019, NSW Annual Report 2019, Ramsay Health Care Annual Report 2019-20, Quarterly Peer Review Reports.

## HREC Approval Number

The Alfred HREC 262/09

## Number of data requests/ad hoc reports (received in 2020)

20+

## PROMs/PREMs collected

N/A

## Number of academic publications (published in 2020)

6

## Funding source

Public sector funding bodies and private/individual hospitals

## Website

[anzscts.org/database](http://anzscts.org/database)

## ACADEMIC LEAD

### Professor Chris Reid

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## CLINICAL LEADS

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ANZSCTS Database Program Chair

### Professor Julian Smith

ANZSCTS Database Research Committee Chair

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# Melbourne Interventional Group Registry (MIG)

## Purpose/aims of the registry

Research

## Population captured

The MIG Registry is a collaborative effort among 6 public hospitals in Melbourne and Geelong.

## Outcomes collected

- mortality – In hospital, 30 days
- in hospital complications – including periprocedural MI, stent thrombosis, urgent CABG, major bleeding, readmissions to hospital

## Year established

2004

## Jurisdictions participating in 2020

Victoria

## Reports published/provided in 2020

N/A

## HREC Approval Number

92/04

## Number of data requests/ad hoc reports (received in 2020)

20 research requests

## PROMs/PREMs collected

EQ5D at 30 days

## Number of academic publications (published in 2020)

9

## Funding source

- Pharmaceutical and device companies

## Website

N/A

## ACADEMIC LEAD

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## CLINICAL LEADS

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### Professor Stephen Duffy

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# National Cardiac Registry (NCR)

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## Purpose/aims of the registry

The National Cardiac Registry (NCR) is a Clinical Quality Registry that will record information on cardiac procedures and devices in order to harness insights to drive better outcomes for all Australians. The NCR's purpose is to identify outcome variance and areas for improvement in the quality of cardiac health care across Australia

NCR objectives:

- utilise a collaborative, federated model for effective engagement, participation and support from stakeholders
- provide a platform to ingest State and Territory data and measure performance as determined by agreed quality indicators
- transparently report on clinical, procedural and patient outcomes to hospitals, clinicians, government and community
- provide national benchmarking of key quality performance measures for cardiac conditions/procedures/devices and secondary prevention

## Population captured

Data will be submitted to the NCR by participating cardiac registries across Australia. The inaugural module of data collection covers patients who undergo a percutaneous coronary intervention (PCI).

## Outcomes collected

PCI outcomes:

- door to reperfusion
- in-hospital and 30-day outcomes, eg. complications, readmission, mortality
- compliance with selected guideline recommendations, eg. lipid lowering therapy and referral to cardiac rehabilitation

## Year established

2019

## Jurisdictions participating in 2020

The NCR utilises a federated model of governance and data collection. Currently there are cardiac registries collecting data in the Australian Capital Territory, New South Wales, Queensland, South Australia and Victoria. Tasmania is working with Victoria's registry to submit data. The Northern Territory and Western Australia are currently developing their registries.

## Reports published/provided in 2020

1

## HREC Approval Number

63109 (Project 59/21)

## Number of data requests/ad hoc reports (received in 2020)

0

## PROMs/PREMs collected

N/A

## Number of academic publications (published in 2020)

0

## Funding source

Australian Government Department of Health

## Website

[nationalcardiacregistry.org.au](http://nationalcardiacregistry.org.au)

# Victorian Cardiac Outcomes Registry (VCOR)

## 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 2020

Victoria, Tasmania

## Reports published/provided in 2020

- VCOR provides quarterly benchmarked quality reports to PCI participating hospitals and DHHS.
- VCOR provides annual benchmarked quality reports to CIED participating hospitals.
- 2019 Annual Report
- Ad hoc reporting to the DHHS Clinical Impacts of COVID-19 Committee
- Reporting to the DHHS Board Safety & Quality Report

## HREC Approval Number

47/12

## Number of data requests/ad hoc reports (received in 2020)

18 research requests

## PROMs/PREMs collected

EQ5D at 30 days post-procedure for PCI patients

## Number of academic publications (published in 2020)

14

## Funding source

VCOR is funded by The Department of Health, Victoria, and In-kind funding from Monash University

## Website

[vcor.org.au](http://vcor.org.au)

## ACADEMIC LEADS

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## CLINICAL LEAD

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### **Professor Sophia Zoungas**

— Head, School of Public Health and Preventive Medicine

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

## 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.

The ANDA audit activity was suspended in 2019 due to the impact of the COVID-19 pandemic and replaced with a survey examining the effect of COVID-19 on diabetes health care delivery nationally.

**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 (data was not collected in 2020).

## Year established

**ANDA:** 2013

**ANDA-L:** 2019

## Jurisdictions participating in 2020

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

## Reports published/provided in 2020

ANDA COVID-19 Service Survey Report 2020

ANDA COVID-19 Service Survey Report

Supplement 2020

## HREC Approval Number

**ANDA** – LNR/17/MonH/123 Monash Health

**ANDA-L** – HREC/48547/MonH-2019 Monash Health

## Number of data requests/ad hoc reports (received in 2020)

**ANDA** – No

**ANDA-L** – No

## PROMs/PREMs collected

N/A

## Number of academic publications (published in 2020)

2

## Funding source

Australian Government Department of Health

## Website

[monash.edu/medicine/anda](http://monash.edu/medicine/anda)

## ACADEMIC LEAD

**Professor Sophia Zoungas**

Head, School of Public Health and Preventive Medicine

## CLINICAL LEAD

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Acute Subacute and Community Program

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# PLANETARY HEALTH







## Professor Michael Abramson

— Acting Director, Monash Centre for Occupational and Environmental Health

## The Australian Mesothelioma Registry (AMR)

### Purpose/aims of the registry

The AMR is a joint collaboration between the Monash Centre for Occupational and Environmental Health (MonCOEH) and the Australian Institute of Health and Welfare (AIHW).

The purpose and aims of the AMR are to:

- better understand the relationship between asbestos exposure and mesothelioma
- better understand the nature and levels of asbestos exposure that can result in mesothelioma
- identify the circumstances under which groups of individuals are exposed to potentially dangerous levels of asbestos and to facilitate prevention
- assist the development of policies to best deal with the asbestos still present in our environment
- provide information to assist researchers in undertaking investigations with the aim of preventing mesothelioma in the future
- identify other exposures that may be associated with mesothelioma
- monitor and report on longitudinal or geographic trends
- inform the development of community education and awareness strategies

### Population captured

All notified mesothelioma cases are included in the registry. Consenting cases are interviewed to assess asbestos exposure in occupational and non-occupational contexts.

### Outcomes collected

Mesothelioma notification data and lifetime exposure data.

### Year established

2010

### Jurisdictions participating in 2020

All Australian jurisdictions, national coverage

### Reports published/provided in 2020

Routine public reports are published annually

### HREC Approval Number

EO2017/4/38 (AIHW Ethics Committee)

### Number of data requests/ad hoc reports (received in 2020)

0

### PROMs/PREMs collected

0

### Number of academic publications (published in 2020)

0

### Funding source

Safe Work Australia

### Website

mesothelioma-australia.com

### ACADEMIC LEAD

#### Professor Michael Abramson

Acting Director, Monash Centre for Occupational and Environmental Health

### CLINICAL LEADS

#### Professor Michael Abramson

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# CLINICAL AND HEALTH DATA OUTCOMES INNOVATION AND RESEARCH



## Professor Susannah Ahern

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- Head, Clinical Outcomes data Reporting and Research Program (CORRP)



## Professor Belinda Gabbe

- Divisional Co-Head Clinical and Health data Outcomes Innovation and Research (CHOIR)



## Professor John McNeil AO

- Sir John Monash Distinguished Professor
- Head, Bariatric Surgery Registry

# Australasian Pelvic Floor Procedure Registry (APFPR)

## ACADEMIC LEAD

**Professor Susannah Ahern**

Head, Clinical Outcomes data Reporting and Research Program

## CLINICAL LEADS

**Urology Craft Group:**

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## REGISTRY CONTACT

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## 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 January 2021. 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 purposes.

## Year established

2019

## Jurisdictions participating in 2020

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

## Reports published/provided in 2020

N/A

## HREC Approval Number

63247

## Number of data requests/ad hoc reports (received in 2020)

N/A

## PROMs/PREMs collected

PROMs are currently in development

## Number of academic publications (published in 2020)

1

## Funding source

Government Department of Health

## Website

apfpr.org.au

# Australian Breast Device Registry (ABDR)

## 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 across Australia.

## 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 (BIA-ALCL)

## Year established

2015

## Jurisdictions participating in 2020

All Australian jurisdictions except Western Australian public sites.

## Reports published/provided in 2020

2019 Annual Report

## HREC Approval Number

HREC/15/Alfred/61

## Number of data requests/ad hoc reports (received in 2020)

Surgeons: 11

Industry: 1 (not proceeded)

Researcher: 4

## PROMs/PREMs collected

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

## Number of academic publications (published in 2020)

3

## Funding source

Commonwealth Government (as represented by Department of Health)

## Website

abdr.org.au

## ACADEMIC LEAD

### Professor Susannah Ahern

Head, Clinical Outcomes data Reporting and Research Program

## 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

#### Elisabeth Elder

Representing Breast Surgeons of Australia and New Zealand (BreastSurgANZ)

## REGISTRY CONTACT

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## Australian Cystic Fibrosis Data Registry (ACFDR)

### ACADEMIC LEAD

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**Dr Rasa Ruseckaite**

Deputy Academic Lead

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Respiratory Physician

### REGISTRY CONTACT

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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 95% 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 2020

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

### Reports published/provided in 2020

2019 Annual Report  
2019 Centre Comparison and Trend reports  
2019 Jurisdictional reports

### HREC Approval Number

HREC/16/Alfred/187

### Number of data requests/ad hoc reports (received in 2020)

15

### PROMs/PREMs collected

Nil

### Number of academic publications (published in 2020)

5

### Funding source

- Cystic Fibrosis Australia
- Vertex Pharmaceuticals

### Website

[cysticfibrosis.org.au/dataregistry](http://cysticfibrosis.org.au/dataregistry)

*“The ACFDR participated in two international CF registry collaborations, publishing early outcomes of COVID-19 in people with CF during 2020.”*

## Australian Dementia Network (ADNeT) Registry

### ACADEMIC LEAD

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data Reporting and  
Research Program

### CLINICAL LEAD

**Dr Stephanie Ward**

Geriatric Medicine

### RESEARCH FELLOW

**Dr Xiaoping Lin**

### REGISTRY CONTACT

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### Purpose/aims of the registry

- Primary aim: to collect and analyse data to monitor and enhance the quality of care and patient outcomes for people diagnosed with either dementia or mild cognitive impairment (MCI) and their caregivers
- Secondary aim: to facilitate the recruitment of participants into research, and establish a resource available to all to assist further study into the risk factors for, and trajectory of dementia and MCI in Australia.

### Population captured

People with a new clinical diagnosis of either dementia or MCI

### Outcomes collected

- baseline and follow-up clinical data
- patient- and carer-reported outcome and experience measures
- periodic data linkage for information routinely collected by various government bodies, such as hospitalisation data

### Year established

2019

### Jurisdictions participating in 2020

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

### Reports published/provided in 2020

0

### HREC Approval Number

HREC: 44037, Alfred Health Local ID: 424/18

### Number of data requests/ad hoc reports (received in 2020)

0

### PROMs/PREMs collected

Collected via patient and carer baseline surveys

### Number of academic publications (published in 2020)

3

### Funding source

National Health and Medical Research Council (NHMRC); The Wicking Trust; The Yulgilbar Foundation; Dementia Australia, and Neuroscience Research Australia (NeuRA)

### Website

[australiandementianetwork.org.au](http://australiandementianetwork.org.au)

# Australian Spine Registry (ASR)

## 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 2020

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 2020

2019 Annual Report

## HREC Approval Number

HREC/16/MH/93

## Number of data requests/ad hoc reports (received in 2020)

0

## PROMs/PREMs collected

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

## Number of academic publications (published in 2020)

0

## Funding source

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

## Website

[spineregistry.org.au](http://spineregistry.org.au)

## ACADEMIC LEAD

**Professor Susannah Ahern**

Head, Clinical Outcomes data Reporting and Research Program

## CLINICAL LEAD

**Mr Michael Johnson**

Orthopaedic Spine Surgeon

## REGISTRY CONTACT

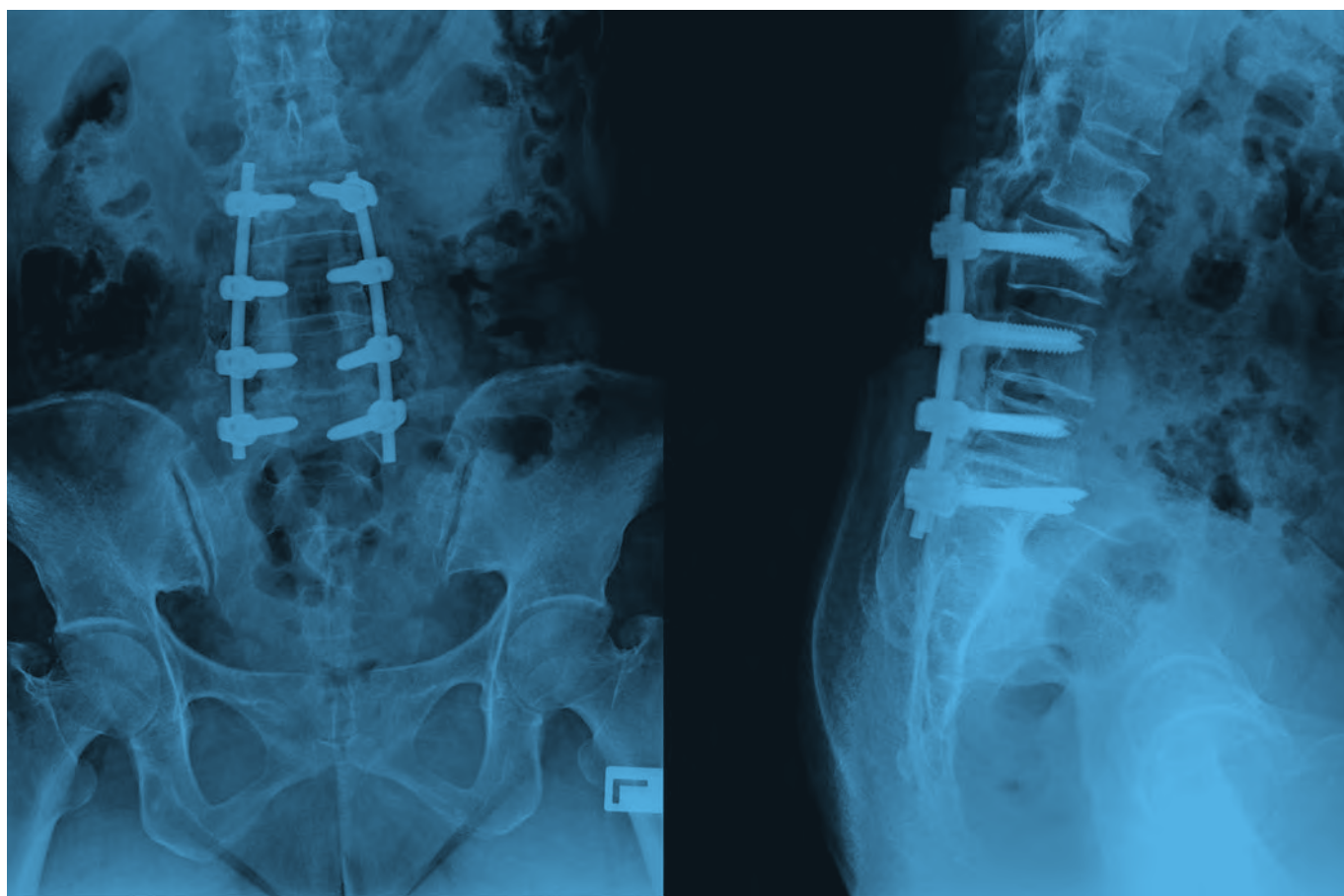
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# Bariatric Surgery Registry (BSR)

## ACADEMIC LEAD

### Professor John McNeil AO

Sir John Monash  
Distinguished Professor

## CLINICAL LEADS

### Professor Wendy Brown

Registry Clinical Director;  
Upper GI and Bariatric  
Surgeon (Australia)

### Associate Professor

#### Andrew MacCormick

Clinical Lead, New Zealand;  
Upper GI and Bariatric Surgeon  
(New Zealand)

## REGISTRY CONTACT

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## 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 persons with obesity 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 collecting any defined adverse events in the first 90 days post-surgery
- studying longitudinally the safety and efficacy of bariatric surgery in Australia and New Zealand
- 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

The incidence of adverse events and deaths related to bariatric surgery are monitored for all participants. Clinical quality indicators within the 3 month period post operatively include:

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

Clinical outcome measures to be collected 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.

## Year established

2012

## Jurisdictions participating in 2020

All States and Territories of Australia and New Zealand

## Reports published/provided in 2020

- Eighth Annual Report of the Bariatric Surgery Registry (as at 30 June 2020)
- Semi-Annual Report (as at 31 December 2019)
- Individual Reports to Participating Surgeons (as at 30 September 2020)

## HREC Approval Number

HREC/18/Alfred/75

## Number of data requests/ad hoc reports (received in 2020)

3

## PROMs/PREMs collected

Patient-Reported Outcome Measures (PROMs) project work is continuing to determine an item bank specific for the bariatric field, in collaboration with both national and international obesity research groups. PROMs will be routinely collected by the Registry in the future.

## Number of academic publications (published in 2020)

0

## Funding source

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

## Website

monash.edu/medicine/sphpm/registries/bariatric



# Specific publications for 2020-2021 relating to the impact of the bushfires and COVID-19 on the registries

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## **FURTHER INFORMATION**

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