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MONASH
CLINICAL REGISTRIES PORTFOLIO 2017

MONASH
PUBLIC HEALTH AND
PREVENTIVE MEDICINE

CONTENTS

> "Clinical registries provide valuable epidemiological data regarding the natural history and progression of diseases … and are used to answer real-world research questions."

Foreword

It is my pleasure to introduce the Monash Clinical Registries Portfolio 2017.

Clinical registries are gaining increasing recognition both within Australia and internationally as a valuable tool in quality improvement. When mature, clinical quality registries monitor key clinical quality indicators and produce benchmarked reports to participating sites that are an effective mechanism of initiating local review and changing clinical practice. In addition, clinical registries provide valuable epidemiological data regarding the natural history and progression of diseases; they are used to answer real-world research questions; they are used to monitor the effect of new pharmaceutical and device treatments over time; and they are starting to be used as platforms on which to undertake clinical studies and clinical trials.

The clinical and health economic value that clinical registries bring was recognised in the 2016 report, Economic Evaluation of Clinical Quality Registries, published by the Australian Commission for Safety and Quality in Healthcare. This report concluded that clinical quality registries may provide a 2- to 7-fold health economic benefit through both a reduction in complications and improvement in overall health outcomes.

This Portfolio provides an annual update regarding the activities and achievements of our Monash Clinical Registries Program. In late 2016 we took over management of the Australian Cystic Fibrosis Data Registry, and in 2017 we established three new clinical registries – the Australian and New Zealand Thyroid Cancer Registry, the Australian Spine Registry, and the National Gynae-Oncology Registry. All of our growing registries have continued to expand their reach across Australia in public and private settings, due to the enthusiasm and participation of clinicians, data managers, researchers and health service managers. Without them, our clinical registry program would not be possible.

I would like to thank our committed registry Steering and other Committee members, advisors, academic leads and operational staff, and wider Monash support staff including information technology, statistics, legal advisors, and the ethics team at Alfred Health, our primary HREC for their hard work, patience and expertise. If you would like any further information regarding Monash's Registry Program or any of the individual clinical registries, please do not hesitate to contact the Registry Science Unit or the individual registry leads.

Best wishes
Professor John McNeil
Head of School

Monash Clinical Registry Initiatives

Registry Data Analysis and Reporting

Monash Clinical Registries utilise the expertise of senior and experienced statisticians and data analysts for all formal reporting and more complex research-related activities. The Registry Science Unit team of data analysts comprises Associate Professor Arul Earnest, Mark Tacey, Breanna Pellegrini and Tom Ranger. Subscribing to the following principles of Reproducibility, Accuracy, Consistency and Validity (RACV), the team also work closely with registry practitioners via a hub and spoke model, to elevate the level of statistical literacy among staff. Specific activities include:

1. Providing statistical support to produce annual reports which are statistically sound and in a timely manner
2. Troubleshooting existing data analytics problems
3. Developing guidelines and operating procedures for the design and analysis of registry data
4. Undertaking quality control audits of data/analysis from registry data
5. Planning and conducting training courses and workshops

The team is also involved in collaborative research with the various registries as well as methodological research, including simulation studies to improve the application of funnel plots for rare/sparse disease outcomes, geo-spatial Bayesian hierarchical models for areal data, risk-adjusted cusum models and reporting checklist for registry data. The team has recently conducted workshops on 'Reporting Registry Data' as well as 'Using Stata for Registry Science' aimed at registry managers and those wishing to gain a better understanding of how to utilise registry data.

PROMs and Monash Clinical Registries

Patient reported outcome measures (PROMs) are recognised as a valuable set of information regarding patients' functional and psychosocial recovery following a disease or procedure. Combined with clinical measures, PROMs can provide a more holistic view of the impact of a disease/procedure on patients and their carers, thus contributing to an overall picture of the value of the healthcare intervention or treatment.

The collection of PROMs generally requires a range of data collection methods, an easy to administer data collection tool, and a clear understanding of the purposes for which the PROMs will be used. Outcomes from PROMs collection and reporting may include evidence to support specific clinical service development or targeted resources at a population level, or provide evidence of variation in patient outcomes at particular participating health services which may require investigation and review.

A number of Monash Clinical Registries are collecting or piloting patient reported outcome measures. These include the Victorian State Trauma Registry, the Victorian Orthopaedic Trauma Outcomes Registry, the Prostate Cancer Outcomes Registry, the Myeloma and Related Diseases Registry, the Australian Spine Registry, the Australian Breast Device Registry and the Bariatric Surgery Registry. In addition, a composite clinical and patient-recorded measure is being developed and trialled for the Victorian Cardiac Outcomes Registry, due to be completed in early 2018.

ACADEMIC LEAD
Associate Professor
Sue Evans
Head, Clinical Registry Unit

REGISTRY CONTACT
Dr Gabriella Tikellis
Registry Coordinator
+61 3 9903 0673
pcor@monash.edu

CLINICAL LEADS
Associate Professor
Jeremy Millar
Radiation Oncology

Professor Mark
Frydenberg
Urology

Professor Ian Davis
Medical Oncology

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.

Jurisdictions participating in 2017

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

Reports published/provided in 2017

Victoria: Clinician and Hospital-based benchmarking (indicator) reports
New Zealand: Clinician and Hospital-based benchmarking (indicator) reports

Funding source

Movember Foundation

Website

pcor.com.au

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 85 per cent of all newly diagnosed cases of prostate cancer in Victoria.

Outcomes collected

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

Jurisdictions participating in 2017

Victoria

Reports published/provided in 2017

Bi-annual clinician and hospital benchmarking reports

Funding source

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

Website

pcr.registry.org.au

ACADEMIC LEAD
Associate Professor
Sue Evans
Head, Clinical Registry Unit

REGISTRY CONTACT
Ms Melanie Evans
+61 3 9903 0245
pcor-vic@monash.edu

CLINICAL LEAD
Associate Professor
Jeremy Millar
Radiation Oncology

ACADEMIC LEAD
Professor John Zalcberg
Coordinating Principal
Investigator

REGISTRY CONTACT
Ms Jennifer Holland
Registry Coordinator
1800 432 231
ugicr@monash.edu

CLINICAL LEADS
Mr Dan Croagh
Hepatopancreatobiliary
Working Party

Professor Wendy Brown
Oesophagogastric
Working Party

Upper Gastrointestinal Cancer Registry (UGICR)

Purpose/aims of the registry

The UGICR is a clinical quality registry which aims to identify variation in treatment and outcomes of individuals newly diagnosed with a primary cancer of the pancreas; oesophagus; stomach; liver; and biliary system. The UGICR will provide benchmarked reports on agreed indicators of best practice to drive improvements in quality of care and patient outcomes.

Population captured

All people aged 18 years or older, who are diagnosed with pancreatic, oesophageal, gastric, primary liver and biliary cancer, that have been diagnosed, assessed or treated in a participating site in Victoria or New South Wales. The registry is currently establishing its pancreatic cancer module in Victoria and New South Wales; and running a pilot of its oesophagogastric module in selected Victorian sites. The additional modules of the registry (biliary and primary liver) are planned for future implementation.

Outcomes collected

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

Jurisdictions participating in 2017

Victoria

Reports published/provided in 2017

N/A

Funding source

Department of Health and Human Services Victoria provided seed funding. The Pancare Foundation and industry partners have also sponsored this registry. NHMRC funding.

Website

ugicr.org.au

National Gynae-Oncology Registry (NGOR)

Purpose/aims of the registry

NGOR is a new clinical quality registry for gynaecological cancers, which is currently piloting the first module, an ovarian cancer registry. Other modules are planned in the future for cancers of the cervix, uterus, vulva, vagina and other gynaecological malignancies. The aim of the registry is to provide benchmarked reports to clinicians on agreed indicators of quality of care, in order to facilitate improvements in care and patient outcomes.

Population captured

The pilot of the ovarian cancer module captures all newly diagnosed patients with ovarian, tubal and peritoneal (OTP) cancers being treated at several participating hospitals in Victoria, New South Wales and Tasmania. The registry plans to expand nationally and to roll out other modules in the future.

Outcomes collected

Ovarian cancer module:

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

Jurisdictions participating in 2017

Victoria, New South Wales, Tasmania

Reports published/provided in 2017

N/A

Funding source

CASS (‘Contributing to Australian Scholarship and Science’) Foundation
Ovarian Cancer Australia
Australian Society of Gynaecologic Oncologists

Website

Under development

ACADEMIC LEAD
Professor John Zalcberg
Head
Cancer Research Program

REGISTRY CONTACT
Ms Natalie Heriot
+61 3 9903 0435
med-cancerregistries
@monash.edu

CLINICAL LEAD
Associate Professor
Robert Rome
Gynaecological Oncologist

Victorian Lung Cancer Registry (VLCR)

ACADEMIC LEAD
Professor John Zalcberg
Cancer Research
Program Lead

REGISTRY CONTACT
Ms Margaret Brand
Registry Coordinator
+61 3 9903 0206
med-vlcr@monash.edu

CLINICAL LEAD
Associate Professor
Rob Stirling
Respiratory Medicine

Purpose/aims of the registry

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

Population captured

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

Outcomes collected

The VLCR provides risk-adjusted, benchmarked reports to participating sites to measure quality of care.
Quality indicator reports sent to participating sites provide measures for: timeliness of care, including time from referral to diagnosis and diagnosis to treatment; quality and access to treatment, including provision of evidence based assessment; delivery of anti-cancer treatment; multidisciplinary care coordination; patient distress screening and supportive care.

Jurisdictions participating in 2017

The VLCR currently collects from 15 sites across metropolitan and regional Victoria, including public and private institutions.

Reports published/provided in 2017

VLCR Annual Report 2015
VLCR Quality Indicator Report 2016

Funding source

DHHS, MRFF, Astra Zeneca, Pfizer

Website

vlcr.registry.org.au

Victorian Cardiac Outcomes Registry (VCOR)

ACADEMIC LEADS
Professor Chris Reid and
Professor Danny Liew
Co-Directors, Monash Centre
of Cardiovascular Research
and Education in Therapeutics

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 three separate modules currently collecting data of interest in cardiovascular care. These include a percutaneous coronary intervention (PCI) clinical quality registry, the early treatment of acute myocardial infarction (STEMI) in rural and regional settings, and data relating to in-hospital management of heart failure. The PCI and STEMI modules directly relate to management of coronary artery disease, primarily in its acute form (heart attacks and angina). The third focuses on chronic heart disease (both coronary and non-coronary) and is undertaken as a one month 'Snapshot' data collection by participating hospitals.

A Cardiac Implantable Electronic Device (CIED) module is soon to be launched at 5 of Melbourne's largest implanting hospitals. It is hoped this activity will expand in 2018 to additional hospitals.

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

Outcomes collected (continued)

STEMI outcomes:

- time to first ECG
- door to needle times
- system delay times
- transfer to PCI capable hospital within 24 hours
- mortality (in-hospital)

Heart failure outcomes:

- guideline recommended therapies
- mortality (in-hospital and 30 days post-discharge)
- readmission 3 months post-discharge

Jurisdictions participating in 2017

Victoria

Reports published/provided in 2017

VCOR provides quarterly benchmarked quality reports to PCI participating hospitals
VCOR provides biannual benchmarked quality reports to STEMI participating hospitals
VCOR provides an annual benchmarked quality report to Heart Failure Snapshot participating hospitals
2016 Annual Report

Funding source

VCOR is funded by The Department of Health, Victoria
NHMRC Centre of Research Excellence in Cardiovascular Outcomes Improvement

Website

vcor.org.au

REGISTRY CONTACT
Ms Angela Brennan
+61 3 9903 0517
angela.brennan@monash.edu

CLINICAL LEAD
Associate Professor
Jeffrey Lefkovits
Cardiology

Melbourne Interventional Group Registry (MIG)

Purpose/aims of the registry

The MIG Registry is a collaborative effort between six public hospitals in Melbourne and Geelong.

The registry aims to provide reliable medium and long-term results (morbidity and mortality) of coronary interventions across Melbourne hospitals.

Population captured

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

Outcomes collected

Mortality – in-hospital, 30 day, 12 month and longer term with linkage to the National Death Index.

In-hospital complications including periprocedural myocardial infarction, stent thrombosis, urgent coronary artery bypass grafts, and major bleeding readmissions to hospital within 12 months of procedure.

Jurisdictions participating in 2017

Victoria

Reports published/provided in 2017

N/A

Funding source

NHMRC Centre of Research Excellence in Cardiovascular Outcomes Improvement. Device and Pharmaceutical companies

Website

monash.edu/medicine/sphpm/registries/mig

ACADEMIC LEAD
Professor Chris Reid
Co-Director, Monash Centre
of Cardiovascular Research
and Education in Therapeutics

REGISTRY CONTACT
Ms Angela Brennan
+61 3 9903 0517
angela.brennan@monash.edu

CLINICAL LEADS
Professor Stephen Duffy
Cardiology

Associate Professor
Andrew Ajani
Cardiology

Associate Professor
David Clark
Cardiology

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

Purpose/aims of the registry

The ANZSCTS National Cardiac Surgery Database Program records details of all adult cardiac surgical procedures performed in participating hospitals. The program publishes comprehensive annual reports describing the activities and outcomes of participating sites in a comparative de-identified format.

Population captured

The Program aims to capture all adult cardiac surgical procedures in Australia including Coronary Artery Bypass Grafts and Valve procedures. The current ANZSCTS inclusion criteria is all patients who undergo cardiac surgery and/or other thoracic surgery using cardiopulmonary bypass and/or pericardiectomy for constrictive pericarditis where bypass has commenced or the pericardium has been opened.

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.

Jurisdictions participating in 2017

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

Reports published/provided in 2017

National Annual Report 2016
Victorian Comprehensive Annual Report 2016
Victorian Public Annual Report 2016
NSW Comprehensive Annual Report 2016
Quarterly Peer Review Reports

Funding source

Public sector funding bodies and private/individual hospitals

Website

anzscts-database.org

ACADEMIC LEAD
Professor Chris Reid
Co-Director, Monash Centre
of Cardiovascular Research
and Education in Therapeutics

REGISTRY CONTACT
Dr Lavinia Tran
+61 3 9903 0229
lavinia.tran@monash.edu

CLINICAL LEADS
Mr Gilbert Shardey
ANZSCTS Database
Program Chair

Mr Julian Smith
ANZSCTS Database
Research Committee Chair

Australian Breast Device Registry (ABDR)

Purpose/aims of the registry

The ABDR is a clinical quality registry for high risk implantable breast devices (implants and expanders). It tracks the outcomes and quality of all breast device surgery performed across Australia. It will benchmark best surgical practice and report progressively on the long term performance of implanted breast devices with the aim of improving patient safety.

Population captured

A population-based pilot registry was established in 2011 with funding from the Australasian Foundation for Plastic Surgery. It was successfully implemented at a small number of public and private health services across Australia.

The registry is now being rolled out to all breast device implanting sites nationwide. It is the first of its type internationally to have breast surgeons, cosmetic surgeons and plastic and reconstructive surgeons contributing data and has become the model registry for several other collaborating countries.

Outcomes collected

Time to revision; postoperative complications (e.g. capsular contracture, infection); mortality; patient Report Outcome Measures (to be collected at follow-up); incidence of breast implant associated anaplastic large cell lymphoma.

Jurisdictions participating in 2017

All Australian jurisdictions

Reports published/provided in 2017

2016 Annual Report

Funding source

Commonwealth Government (as represented by Department of Health)

Website

abdr.org.au

ACADEMIC LEAD
Dr Ingrid Hopper
Head
Drug and Device Registries

REGISTRY CONTACT
Ms Catherine Mulvany
+61 3 9903 0205
abdr@monash.edu

CLINICAL LEADS
Professor Rod Cooter
Plastic Surgeon

Associate Professor
Colin Moore
Cosmetic Surgeon

Associate Professor
Elisabeth Elder
Breast Surgeon

ACADEMIC LEAD
Professor John McNeil
Head, School of Public Health
and Preventive Medicine

REGISTRY CONTACT
Ms Brooke Backman
+61 3 9903 0725
med-bsr@monash.edu

CLINICAL LEADS
Professor Wendy Brown
Oesophagogastric Surgeon

Associate Professor
Andrew MacCormick
Upper GI and
Bariatric Surgeon, NZ

Bariatric Surgery Registry (BSR)

Purpose/aims of the registry

The Bariatric Surgery Registry is a population-based registry which aims to measure benchmark outcomes for patients undergoing bariatric surgery in Australia and New Zealand.

The Bariatric Surgery Registry does this by: recording the immediate safety of bariatric surgery in Australia and New Zealand; 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 their peers.

Population captured

The BSR collects data about patients undergoing bariatric surgery in public and private hospitals across Australia and New Zealand.

Outcomes collected

The BSR collects information about the quality and safety of bariatric surgery in the immediate perioperative period and over the long-term. Clinical quality indicators include defined adverse events in perioperative period, mortality and need for reoperation in primary patients over at least 10 years. Clinical outcome measures in primary patients include excess weight loss and changes in diabetes treatment over at least 10 years.

Jurisdictions participating in 2017

All States and Territories of Australia and New Zealand

Reports published/provided in 2017

Fifth Annual Report of the Bariatric Surgery Registry (as at 30 June 2017)
Semi-Annual Update (as at 31 December 2016)
Individual Report to Participating Surgeon (as at 30 September 2017)

Funding source

Commonwealth Government Department of Health Industry Partners – Applied Medical, Medtronic and Gore

Website

monash.edu/medicine/sphpm/registries/bariatric

ACADEMIC LEAD
Professor Rachelle Buchbinder
Director, Monash Department of Clinical Epidemiology, Cabrini Institute

REGISTRY CONTACT
Mr Ashley Fletcher
+61 3 9508 3473
arad@monash.edu

CLINICAL LEADS
Professor Rachelle Buchbinder
Rheumatology

Professor Lyn March
Rheumatology

Professor Marissa Lassere
Rheumatology

Professor Catherine Hill
Rheumatology

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 spondyloarthritis, 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.

Jurisdictions participating in 2017

Australia

Reports published/provided in 2017

Annual – personalised for Rheumatologists

Funding source

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

Website

arad.org.au/

Registry of Kidney Diseases (ROKD)

Purpose/aims of the registry

The aims of the ROKD are to:

- improve understanding of the clinical features and natural history of a series of uncommon kidney diseases
- identify factors that predict prognosis and outcomes, particularly in relation to progression to end stage kidney disease, cardiovascular events and death
- measure and benchmark current patterns of care and clinical practice
- improve evidence of best practice for patient management
- reduce variation in treatment approaches
- improve outcomes as a result of a more systematic implementation of evidence-based guidelines

Population captured

The ROKD includes patients newly diagnosed with specific renal diseases.

Outcomes collected

Mortality, progression to dialysis, progression to transplant, complications of disease, and complications of therapies.

Jurisdictions participating in 2017

Victoria

Reports published/provided in 2017

N/A

Funding source

Industry partners

Website

rokd.org.au

ACADEMIC LEAD
Professor John McNeil
Head, School of Public Health and Preventive Medicine

REGISTRY CONTACT
Ms Claire Galbraith
1800 811 326
sphpm-rokd@monash.edu

CLINICAL LEAD
Professor Rowan Walker
Nephrology

Australian Cystic Fibrosis Data Registry (ACFDR)

Purpose/aims of the registry

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

Population captured

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

Outcomes collected

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

Jurisdictions participating in 2017

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

Reports published/provided in 2017

2015 Annual Report
2015 Centre Trend and comparison site reports
2015 Jurisdictional reports

Funding source

Cystic Fibrosis Australia

Website

cysticfibrosis.org.au/data-registry

ACADEMIC LEAD
Associate Professor
Susannah Ahern
Head, Registry Science Unit

REGISTRY CONTACT
Ms Joanna Dean
+61 3 9903 0101
joanne.dean@monash.edu

CLINICAL LEAD
Professor Scott Bell
Respiratory Physician

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 18 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, Western Australia and Queensland. The registry will also expand to include sites in New Zealand.

Outcomes collected

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

Jurisdictions participating in 2017

Victoria

Reports published/provided in 2017

N/A

Funding source

The Australian and New Zealand Endocrine Surgeons (ANZES), industry, and a grant from the Alfred Foundation

Website

Under development

ACADEMIC LEAD
Associate Professor
Susannah Ahern
Head, Registry Science Unit

REGISTRY CONTACT
Dr Liane Ioannou
+61 3 9903 0046
sphpm.anztcr@monash.edu

CLINICAL LEAD
Professor Jonathan Serpell
Endocrine Surgeon

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.

Jurisdictions participating in 2017

The registry is in a pilot stage with recruitment commencing early 2018. The pilot involves public and private health service sites in Victoria, New South Wales, Western Australia and Tasmania.

Reports published/provided in 2017

Annual Progress Report 2017

Funding source

The Spine Society of Australia, BUPA and the following medical device companies: DePuy Synthes (Johnson & Johnson), LifeHealthcare, Medtronic, NuVasive, Stryker, Zimmer.

Website

spineregistry.org.au

ACADEMIC LEAD
Associate Professor
Susannah Ahern
Head, Registry Science Unit

REGISTRY CONTACT
Dr Esther Apos
+61 3 9903 0782
0419 632 587
esther.apos@monash.edu
spineregistryAU@monash.edu

CLINICAL LEAD
Mr Michael Johnson
Orthopaedic Spine Surgeon

Aplastic Anaemia Registry (AAR)

Purpose/aims of the registry

The aims of the AAR are to:

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

Population captured

Adult and paediatric patients suffering from aplastic anaemia.

Outcomes collected

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

Jurisdictions participating in 2017

Australia

Reports published/provided in 2017

N/A

Funding source

Maddie Riewoldt's Vision

Website

torc.org.au/aar

ACADEMIC LEAD
Associate Professor
Erica Wood
Head
Transfusion Research Unit

REGISTRY CONTACT
Dr Luke Rowsell
1800 811 326
aar@monash.edu

CLINICAL LEAD
Professor Frank Firkin
Haematology

Australian New Zealand Massive Transfusion Registry (ANZ-MTR)

ACADEMIC LEAD
Associate Professor
Erica Wood
Head
Transfusion Research Unit

REGISTRY CONTACT
Dr Rosemary Sparrow /
Mrs Helen Haysom
1800 811 326
sphpm.mtr@monash.edu

CLINICAL LEADS
Professor James Isbister
Haematology

Dr Zoe McQuilten
Haematology

Purpose/aims of the registry

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

Population captured

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

Outcomes collected

Demographics, diagnoses, hospital admission details, transfusion information on all fresh blood products, plasma products and adjunctive therapies, as well as laboratory results for the patient's hospital admission. Patient outcomes include patient discharge and in-hospital mortality information.

Long term outcomes are available through data linkages with death and other registries (i.e. death data).

Jurisdictions participating in 2017

Australia and New Zealand

Reports published/provided in 2017

Hospital Data Reports
ANZ-MTR Newsletter

Funding source

NHMRC partnership grant, Australian National Blood Authority, Australian Red Cross Blood Service CSL Behring, New Zealand Blood Service, St John of God Pathology, Department of Health and Human Services Victoria.

Website

monash.edu/medicine/sphpm/registries/anz-mtr

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 in this area

Population captured

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

Outcomes collected

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

Jurisdictions participating in 2017

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

Reports published/provided in 2017

N/A

Funding source

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

Website

monash.edu/medicine/sphpm/registries/hbr

ACADEMIC LEAD
Associate Professor
Erica Wood
Head
Transfusion Research Unit

REGISTRY CONTACT
Associate Professor
Erica Wood
1800 811 326
hbr@monash.edu

CLINICAL LEAD
Professor Joy Ho
Haematology

Lymphoma and Related Diseases Registry (LaRDR)

ACADEMIC LEAD
Associate Professor
Erica Wood
Head
Transfusion Research Unit

REGISTRY CONTACT
Dr Luke Rowsell
1800 811 326
sphpm-lymphoma
@monash.edu

CLINICAL LEADS
Associate Professor
Stephen Opat
Haematology

Dr Zoe McQuilten
Haematology

Purpose/aims of the registry

The aims of the LaRDR are to:

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

Population captured

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

Outcomes collected

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

Jurisdictions participating in 2017

Australia

Reports published/provided in 2017

N/A

Funding source

Industry partners

Website

lardr.org

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

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

Outcomes collected

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

Jurisdictions participating in 2017

Australia and New Zealand

Reports published/provided in 2017

Annual Report

Funding source

Industry partners

Website

mrdr.net.au

ACADEMIC LEAD
Associate Professor
Erica Wood
Head
Transfusion Research Unit

REGISTRY CONTACT
Dr Elizabeth Moore
1800 811 326
sphpm-myeloma
@monash.edu

CLINICAL LEAD
Professor Andrew Spencer
Haematology

Neonatal Alloimmune Thrombocytopenia (NAIT) Registry

ACADEMIC LEAD
Associate Professor
Erica Wood
Head
Transfusion Research Unit

REGISTRY CONTACT
Associate Professor
Erica Wood
1800 811 326
med-nait@monash.edu

CLINICAL LEADS
Dr Stephen Cole
Obstetrics

Dr Gemma Crighton
Paediatric Haematology

Purpose/aims of the registry

The aims of the registry are to:

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

Population captured

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

Outcomes collected

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

Jurisdictions participating in 2017

All Australian jurisdictions

Reports published/provided in 2017

Presentation of the NAIT Registry's work at the Victorian Immunohaematology Discussion Group meeting in West Melbourne on 12 September 2017.

Funding source

In-kind support for the NAIT Registry is provided by the Blood Service and Monash University's Department of Epidemiology and Preventive Medicine.

Website

monash.edu/medicine/sphpm/registries/nait

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

Purpose/aims of the registry

The aims of the TTP/TMA Registry are to:

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

Population captured

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

Outcomes collected

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

Jurisdictions participating in 2017

Australia and New Zealand

Reports published/provided in 2017

Annual Report

Funding source

Industry partners

Website

monash.edu/medicine/sphpm/registries/ttp

ACADEMIC LEAD
Associate Professor
Erica Wood
Head
Transfusion Research Unit

REGISTRY CONTACT
Ms Kelly Burns
1800 811 326
med-ttpregistry@monash.edu

CLINICAL LEAD
Associate Professor
Shiomo Cohney
Nephrology

Dr Piers Blombery
Haematology

ACADEMIC LEAD
Associate Professor
Erica Wood
Head
Transfusion Research Unit

REGISTRY CONTACT
Associate Professor
Erica Wood
1800 811 326
sphpm.vteregistry
@monash.edu

CLINICAL LEAD
Dr Huyen Tran
VTE Steering Committee

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

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

Outcomes collected

Outcome of VTE episode, complications of episode, complications of therapy, representations of VTE.

Jurisdictions participating in 2017

Victoria

Reports published/provided in 2017

N/A

Funding source

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

Website

monash.edu/medicine/sphpm/registries/vte

Photo credit: Alfred Health

ACADEMIC LEAD
Professor Peter Cameron
Emergency Medicine and
Divisional Head of Health
Services Research

REGISTRY CONTACT
Ms Jane Ford
+61 3 9903 0408
jane.ford@monash.edu

CLINICAL LEADS
Professor Peter Cameron
Emergency Medicine

Professor Mark Fitzgerald
Trauma Physician

Australian Trauma Registry (ATR)

Purpose/aims of the registry

The ATR is a major 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 provided by the 26 hospitals designated as major trauma centres (MTCs) in Australia. Some of the information that is already routinely collected by MTCs about severely injured patients is de-identified, standardised and electronically submitted to the ATR, currently in yearly increments but shortly on a quarterly basis. As the registry grows, reports will be released that will enhance the development of risk-adjusted models for benchmarking designated trauma centres, quality indicators and calculating the true cost of trauma care.

Population captured

All patients that meet criteria who present to each of the collaborating sites.

Outcomes collected

The dataset includes but is not limited to the details of the injury event, the nature of the injuries that were sustained, the treatment received and the discharge status – the full patient journey through the Australian hospital system.

Jurisdictions participating in 2017

Major trauma centres in all Australian states and territories. This is a collaboration with the NTRI.

Reports published/provided in 2017

Consolidated Report 1/1/2013 – 30/6/2015

Funding source

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

Website

ntri.org.au/australian-trauma-quality-improvement-program-and-the-australian-trauma-registry

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Burns Registry of Australia and New Zealand (BRANZ)

Purpose/aims of the registry

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

Population captured

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

Outcomes collected

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

Jurisdictions participating in 2017

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

Reports published/provided in 2017

Annual report 2015-16

Funding source

Australian and New Zealand Burns Association, Helen Macpherson Smith Trust, Julian Burton Burns Trust, Thyne Reid Foundation, Australasian Foundation for Plastic Surgery, New Zealand Accident Compensation Corporation, Individual Burn Units

Website

branz.org

ACADEMIC LEAD
Professor Belinda Gabbe
Head
Pre-Hospital, Emergency
and Trauma Research Unit

REGISTRY CONTACT
Dr Lincoln Tracy or
Dr Judy McInnes
+61 3 9903 0288
anzba.registry@monash.edu

CLINICAL LEAD
Dr Heather Cleland
Plastic Surgeon

ACADEMIC LEAD

Professor Belinda Gabbe
Head
Pre-Hospital, Emergency
and Trauma Research Unit

REGISTRY CONTACT

Ms Melissa Hart
+61 3 9903 0113
melissa.hart@monash.edu

CLINICAL LEADS

Associate Professor
Elton Edwards
Orthopaedic

Associate Professor
Sue Liew
Orthopaedic

Associate Professor
Raphael Hau
Orthopaedic

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 (Department of Trauma Surgery) and the Royal Melbourne Hospital (Department of Orthopaedics). The registry is a comprehensive database of orthopaedic injuries, treatment, complications and outcomes based on admissions to The Alfred, Royal Melbourne, University Hospital Geelong and Northern Hospitals. The overarching aims are to: monitor orthopaedic injury management, identify 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 for an orthopaedic injury. Patients with a pathological fracture related to metastatic disease are excluded. Eligible patients are identified by the discharge diagnosis through ICD-10-AM reports from the hospitals.

Outcomes collected

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

Jurisdictions participating in 2017

Victoria (Sentinel site registry)

Reports published/provided in 2017

VOTOR Annual Report which is available on the VOTOR website

Funding source

Transport Accident Commission (TAC)

Website

votor.org.au

Victorian State Trauma Registry (VSTR)

Purpose/aims of the registry

The Victorian Department of Human Services (now Department of Health and Human Services) commissioned the VSTR in 2001 in collaboration with the Transport Accident Commission Health Research.

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

Population captured

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

Outcomes collected

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

Jurisdictions participating in 2017

138 participating hospitals in Victoria.

Reports published/provided in 2017

Quarterly Reports, Annual Reports

Funding source

Department of Health and Human Services, Transport Accident Commission

Website

vstorm.monash.org

ACADEMIC LEAD

Professor Belinda Gabbe
Head
Pre-Hospital, Emergency
and Trauma Research Unit

REGISTRY CONTACT

Ms Mimi Morgan
+61 3 9903 0996
mimi.morgan@monash.edu

CLINICAL LEAD

Professor Peter Cameron
Emergency Medicine

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

ACADEMIC LEAD
Professor Judith Finn
Director, Australian
Resuscitation Outcomes
Consortium (Aus-ROC)

REGISTRY CONTACT
Dr Ben Beck
Coordinator, Aus-ROC Epistry
+61 3 9903 0316
ben.beck@monash.edu

CLINICAL LEADS
Associate Professor
Janet Bray
Associate Director, Australian
Resuscitation Outcomes
Consortium (Aus-ROC)

Professor Peter Cameron
Emergency Medicine

Purpose/aims of the registry

A key aim of the Aus-ROC CRE was to establish an Australian and New Zealand out-of-hospital cardiac arrest (OHCA) 'Epistry' (epidemiologic registry). Specifically, the Aus-ROC Epistry was established with the aim of understanding regional, ambulance service and treatment factors associated with improved OHCA survival and outcomes. The scope of the Epistry will enable a range of important research questions to be answered, including: understanding regional variations in outcome; the impact of variations in the provision of treatment for OHCA between ambulance services; temporal changes in incidence and outcome; and the impact of changes in clinical guidelines and clinical trials.

Population captured

All out-of-hospital cardiac arrest patients in 5 states and territories in Australia (South Australia, Western Australia, Victoria, Queensland and the Northern Territory) and all of New Zealand. The total catchment population is approximately 19.8 million persons, representing 64% of the Australian population and 100% of the New Zealand population.

Outcomes collected

Survival (prehospital, in-hospital or 30 days)

Jurisdictions participating in 2017

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), and New Zealand (St John New Zealand and Wellington Free Ambulance)

Reports published/provided in 2017

N/A

Funding source

NHMRC Centre of Research Excellence: the Australian Resuscitation Outcomes Consortium

Website

ausroc.org.au

International Collaboration of Breast Registries Activities (ICOBRA)

The International Collaboration of Breast Device Registries Activities (ICOBRA) commenced in 2013, and was developed to establish an internationally agreed and comparable minimum data set for breast device registries, comprised of standardised and epidemiologically sound data that reflect global best practice in breast implant surgery. Contributing countries and organisations include national plastic and reconstructive surgery societies, national health services and national health regulatory agencies. Currently 20 countries are signatories. At the heart of the ICOBRA concept is the core ethic and commitment to improving patient outcomes. The group met at the Monash campus in Prato, Italy in 2017. The Australian Breast Device Registry has been leading two international panels to establish a global minimum data set, and global quality indicators to facilitate international benchmarking.

Saudi Arabia Trauma Registry (STAR)

The Saudi Arabia Trauma Registry is a collaboration with King Saud Medical City to establish a hospital registry in Riyadh, and commenced in mid 2017.

The STAR Registry is currently in a pilot phase. The intention is to establish a national registry to examine epidemiology of major trauma, medical processes and treatments and risk adjusted outcomes; this will enable international comparisons. Currently the incidence of major trauma is much higher in Saudi Arabia than most developed countries and there is a national focus on improving injury prevention and outcomes

TrueNTH Global Registry

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

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

As the Data Coordination Centre (DCC), Monash University is the centre receiving and housing data transferred from 23 Local Data Centres (LDCs), representing more than 160 healthcare institutions across 13 countries. The DCC oversees data management and developed the TrueNTH Global Registry, its data dictionary and the protocol; built a technical solution for the secure transfer of data from sites to the DCC and is on an ongoing basis providing training to sites on its use. Monash will provide a research portal to enable participating sites to gain secure access to data (following relevant ethical approval); and is leading development of quality indicators to report back to participating sites.

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FURTHER INFORMATION

Registry Science Unit
Epidemiology and Preventive Medicine
Monash Public Health and Preventive Medicine
Monash University, 553 St Kilda Road, Melbourne VIC 3004

T: +61 3 9903 0463
F: +61 3 9903 0556
E: med-clinicalregistries@monash.edu

CRICOS provider: Monash University 00008C.
Produced by Monash SMC. 18P-0011 March 2018