MONASH CLINICAL REGISTRIES PORTFOLIO 2017

MONASH PUBLIC HEALTH AND PREVENTIVE MEDICINE
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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

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

Website
pcr.registry.org.au

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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 oesophago-gastric 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 ovari, 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**
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.

**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

**Website**
Under development
**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 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)

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

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

ACADEMIC LEADS
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Outcomes collected (continued)

Registries

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CARDIAC REGISTRIES

CARDIAC REGISTRIES
Melbourne Interventionsal 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, ventricular fibrillation, 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

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

Purpose/aims of the registry
The ANZSCCTS 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 ANZSCCTS 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

Funding source
Public sector funding bodies and private/individual hospitals

Website
anzscts-database.org
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

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Cosmetic Surgeon
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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
### 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 (DMARD) therapies together with a group of patients not receiving DMARDs 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 spondylitis, 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 – personalized 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**

rok.org.au
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

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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

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, surgery, pathology, treatment and outcomes, 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
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
Australian New Zealand Massive Transfusion Registry (ANZ-MTR)

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

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

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

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

**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

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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

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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

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

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Neonatal Alloimmune Thrombocytopenia (NAIT) Registry

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 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
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
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

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
**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, 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

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**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

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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 23 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.


Kimmel L. Patient perception of discharge from hospital following trauma: A case for increased patient involvement in follow-up care. The Health Advocate 2017; 41:36-37


FURTHER INFORMATION

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