MONASH
CLINICAL REGISTRIES PORTFOLIO 2016

MONASH
PUBLIC HEALTH AND PREVENTIVE MEDICINE
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“It is a very exciting time to be involved in the development and ongoing evolution of clinical registries in Australia”
Foreword

I am very proud to present the Inaugural Monash Clinical Registries Portfolio 2016. This Portfolio is designed to provide an overview of the clinical registries currently operating at Monash University within the Monash Clinical Registries Program.

It is a very exciting time to be involved in the development and ongoing evolution of clinical registries in Australia. Monitoring variation in healthcare is known to support best practice and improve quality of care. However, challenges exist in developing and accessing appropriate data sets on which to undertake clinical quality benchmarking. Clinical registries are increasingly recognised as credible, effective and feasible tools to measure variation and drive quality improvement at the national and jurisdictional health system levels.

Clinical Quality Registries:
- are designed to collect clinically relevant data about episodes of care and its outcomes
- collect data systematically using standard procedures and definitions across multiple institutions
- routinely measure outcomes following discharge at a time when the impact of any intervention or treatment and the extent of recovery can be judged
- are more likely to influence clinical practice because clinical leadership participates in design and ongoing oversight, and the data has greater granularity and reliability.

The Monash Clinical Registries Program now boasts 22 registries managed in-house as well as ‘external’ registries supported by our information technology capability. Clinical registry participation is now seen as a valuable tool for health service accreditation and clinician professional development.

The Monash Clinical Registries Program would not be possible without the hard work, patience and commitment of our Registry Clinical Leaders, Steering and other Committee Members, registry staff, health service staff and clinicians. If you would like further information regarding Monash’s Registry Program, please contact the Registry Sciences Unit or the individual registry contacts.

Best wishes

John McNeil
Preparing Clinical Registries for the Future

The potential of clinical registries to support quality improvement and clinical research into the future is significant. Advances in information technology are enhancing the capacity for data sharing and linkage, increasing access to meaningful clinical information and improving the efficiency and effectiveness of data collection. New technology applications allow for more secure data management and transfer, and support regular high quality statistical reporting of large datasets.

Genetic and genomic data as well as biobanks have the potential to be incorporated within registry datasets, leading to the integration of clinical, genetic and epidemiological information. This can then provide a greater potential to answer clinical and quality research questions that can improve patient outcomes.

Monash Clinical Registries are underpinned by extensive information technology capability, statistical and data analytics skills, clinical and epidemiological research expertise, high quality operational and service functionality, and robust governance and academic leadership. They are driven by a collaborative model of clinician leadership and peer review, ensuring that registry data is high quality, valid, reliable and useful for clinicians, hospitals, researchers, governments and other stakeholders.

In 2016, the Monash Clinical Registries Program established a Registry Sciences Unit which comprises a multidisciplinary team who work with clinicians and funders to develop potential new registries, as well as provide support and advice to existing clinical registries. Dr Susannah Ahern, a medical administrator and academic, is Head of the Registry Sciences Unit. She oversees the Unit to develop initiatives and products that will support best practice and continuous improvement across the Registry Program, in collaboration with the Registry Leaders. Associate Professor Sue Evans drives the overall registry academic program, leading a regular Registry Special Interest Group which is open to interested participants, including those external to the School.
Monash Clinical Registries Overview
Australian Prostate Cancer Registry (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
The registry is collecting data from each Australian jurisdiction and from New Zealand.

Outcomes collected
Patient-reported quality of life, progression, survival and quality.

Funding source
Movember Foundation.

Website
pcor.com.au
Upper Gastrointestinal Cancer Registry (UGICR)

Purpose/aims of the registry
The UGICR is a new clinical quality registry designed to describe patterns of care following diagnosis of primary cancers of the pancreas, oesophagus, stomach, liver and biliary system (i.e. upper gastrointestinal cancers) with a view to improving patient outcomes and quality of care.

Population captured
All persons over 18 years of age in Victoria diagnosed with pancreatic, oesophageal, gastric, primary liver and/or biliary cancer with some tumour types excluded (eg. upper 1/3 oesophageal cancers). Currently the registry is in a pilot stage collecting data on only pancreatic cancer cases. Additional modules (i.e. other cancer types) will be added at a later date. The pilot phase only involves three main health services, but the UGICR will eventually include approximately 30 major sites around Victoria.

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

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

Website
med.monash.edu.au/sphpm/depts-centres-units/registries/ugicr.html
Victorian Lung Cancer Registry (VLCR)

Purpose/aims of the registry
The VLCR aims to record all newly diagnosed lung cancer cases in participating sites in Victoria. Information from the registry will be used to monitor care provided, including treatment, complications and both short and longer term outcomes of care. This information will be used to help identify trends and whether gaps exist in service provision.

Population captured
The VLCR aims to record all newly diagnosed lung cancer cases in participating sites in Victoria. The pilot registry will focus on the adult population (over the age of 18) seen in key central lung cancer care referral centres across Melbourne and will ultimately include regional and rural centres of care.

Outcomes collected
– Identifying variability in treatment among individuals for lung cancer and studying its causes and consequences
– Determining the degree of compliance (and reasons for noncompliance) with evidence-based guidelines for the treatment of lung cancer
– Identifying factors that predict favourable and unfavourable treatment outcome.

A lung cancer registry will provide the opportunity to improve knowledge of the disease and advance treatment by:
– monitoring trends in stage and treatment-specific survival of lung cancer
– providing an infrastructure on which intervention or other studies can be established
– determining the clinical effectiveness of treatments in a ‘real world’ setting.

Funding source
Victorian Cancer Agency.

Website
vlcr.registry.org.au
Victorian Prostate Cancer Registry (PCR)

Purpose/aims of the registry
The Victorian PCR 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
- General health and disease-specific quality of life at 12 and 24 months post diagnosis
- Treatment failure
- Biochemical recurrence
- Process indicators: positive margin rate post prostatectomy, documentation of clinical stage, PSA recorded post prostatectomy, advanced disease and active surveillance.

Funding source
Movember Foundation
Cancer Australia.
Prostate Cancer Foundation of Australia
Department of Health and Ageing
Victorian Department of Health.

Website
pcr.registry.org.au
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 onto 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.

Funding source
Pharmaceutical and device companies.

Website
med.monash.edu.au/sphpm/depts-centres-units/registries/mig.html
The 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 day post-surgery)
- Complications including cardiac, neurological, renal, infections, gastrointestinal and return to theatre
- Readmissions within 30 days post-surgery.

Funding source
Public sector funding bodies and private/individual hospitals.

Website
anzscts-database.org

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Mr Gilbert Shardey
ANZSCTS Database Program Chair

Mr Julian Smith
ANZSCTS President and Research Committee Chair
**Purpose/aims of the registry**

Heart disease has an impact on both the individual and the community, therefore it is critical that public health initiatives and policies are directed at delivering treatment with high levels of safety and quality. 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. The aim of the registry is to measure and report on trends in the quality of patient care over time, within individual hospitals, comparatively with other hospitals, and aggregated at the state level. The goal is to foster continuous improvement in patient care and outcomes across the entire Victorian health system.

**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.

As at July 2016, the PCI registry contains over 25,000 cases, including data from all public hospitals performing PCI and 14 out of 17 private hospitals that perform PCI. The STEMI module has captured over 240 cases in the six pilot hospitals and in 2016 is expanding to an additional five regional hospitals. The heart failure Snapshot has collected over 900 cases across three separate years, with the most recent in 2016 being done by 16 hospitals, including a private hospital.

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**CLINICAL LEADER**
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Cardiology
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 30 days post-discharge.

Funding source
VCOR is funded by The Department of Health, Victoria.

Website
vcor.org.au

REGISTRY CUSTODIANS
Professor Danny Liew
Co-Director, Monash Centre of Cardiovascular Research and Education in Therapeutics
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 report progressively on the long term performance of implanted 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 rolled out to 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).

Funding source
Commonwealth Government (as represented by Department of Health).

Website
abdr.org.au
Bariatric Surgery Registry

Purpose/aims of the registry
The bariatric surgery registry aims to:
– record the immediate safety of bariatric surgery in Australia and New Zealand
– study longitudinally the safety and efficacy of bariatric surgery in Australia and New Zealand
– track key health changes following bariatric surgery in Australia and New Zealand.

Population captured
A population-based registry which aims to measure outcomes for patients undergoing bariatric surgery across surgical practices in Australia and New Zealand.

Outcomes collected
Clinical quality indicators – defined adverse events in perioperative period, mortality and reoperation in primary patients over 10 years.

Clinical outcomes in primary patients (over 10 years): excess weight loss and changes in diabetes treatment.

Funding source

Website
med.monash.edu.au/sphpm/depts-centres-units/bariatric
Australian Rheumatology Association Database (ARAD)

Purpose/aims of the registry
The ARAD is a national Australian database which collects important health information from individuals with inflammatory arthritis. The aim of ARAD is to determine the short and long term effectiveness and safety of new biological drugs used to treat inflammatory arthritis conditions.

Population captured
Australians with a form of inflammatory arthritis are eligible to enrol in this voluntary registry.

Outcomes collected
The ARAD collects information from patients at six to 12 monthly intervals via paper-based and online questionnaires. Questions about medical history, medication history, responses to medication, physical functioning and quality of life are asked.

Funding source
NHMRC Enabling Grant, Monash University and unrestricted educational grants administered by the Australian Rheumatology Association.

Website
arad.org.au
Registry of Kidney Diseases (ROKD)

Purpose/aims of the registry
The aims of the ROKD are to:
- increase the accuracy of estimates of specific renal disease incidence and prevalence
- increase the accuracy of estimates of chronic kidney disease incidence and prevalence
- improve understanding of the phenotypic expression and natural history of disease
- identify factors that predict prognosis and outcomes, particularly in relation to progression to end stage kidney disease (dialysis/transplantation), cardiovascular events or death
- assess current patterns of care and clinical practice
- improve evidence for best practice-based guidelines for patient management
- reduce variation in treatment and improve outcomes as a result of better 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.

Funding source
Industry partners.

Website
rokd.org.au
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, and clinical outcomes; if death, cause of death.

Funding source
Maddie Riewoldt’s Vision.

Website
torc.org.au/aar
Australian and New Zealand Massive Transfusion Registry (ANZ-MTR)

Purpose/aims of the registry
The aims of the ANZ-MTR are 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 more than five units of red blood cells within any four hour time period.

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).

Funding source
NHMRC partnership grant.

Website
torc.org.au
Purpose/aims of the registry
The aims of the HbR are to:
– monitor trends in incidence and survival
– monitor access to care
– 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, ß-thalassemia major and other haemoglobinopathies.

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

Funding source
Industry partners.

Website
torc.org.au
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).

Funding source
Industry partners.
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
– to 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, and clinical outcomes (include mortality, disease progression, best clinical response to therapy and quality of life).

Funding source
Industry partners.

Website
mrdr.net.au
Neonatal Alloimmune Thrombocytopenia (NAIT) Registry

Purpose/aims of the registry
The aims of the NAIT Registry are to:
– better define the incidence, natural history and clinical outcome of NAIT
– provide information on the range of therapeutic strategies being employed in the treatment of NAIT patients
– explore factors influencing clinical outcomes
– better define optimal management of NAIT patients
– 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.

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
torc.org.au
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.

Funding source
Industry partners.

Website
torc.org.au/ttp
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.

Funding source
National Critical Care and Trauma Response Centre, Alfred Health.

Website
Under development
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.

Funding source
Australian and New Zealand Burns Association
Julian Burton Burns Trust
Australasian Foundation for Plastic Surgery
Individual burns units.

Helen Macpherson Smith Trust
Thyne Reid Foundation
New Zealand Accident Compensation Corporation

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 (Department of Epidemiology and Preventive Medicine), the Alfred (Department of Trauma Surgery) and the Royal Melbourne Hospital (Department of Orthopaedics). The registry is a comprehensive database of orthopaedic injuries, treatment, complications and outcomes based on admissions to the adult Major Trauma Service (MTS) hospitals in Victoria.

Population captured
The aim of the registry is to collect information about orthopaedic injuries, treatment, complications and outcomes based on admissions to the adult MTS hospitals in Victoria, as well as University Hospital Geelong and The Northern Hospital.

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.

Funding source
Institute of Safety Compensation Recovery and Research.

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.

Funding source
Department of Health and Transport Accident Commission.

Website
vstorm.monash.org
FURTHER INFORMATION

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