MONASH University

MONASH
CLINICAL REGISTRIES PORTFOLIO 2016

MONASH
PUBLIC HEALTH AND
PREVENTIVE MEDICINE

CONTENTS

CANCER REGISTRIES

CARDIAC REGISTRIES

DEVICE/PROCEDURE REGISTRIES

MEDICAL REGISTRIES

TRANSFUSION AND BLOOD DISEASES

TRAUMA REGISTRIES

Monash registry academics and Registry Sciences Unit staff

"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

Head of Deptartment
John McNeil

Monash Clinical Registries

Cancer
John Zalzberg

Trauma
Belinda Gabbe

Transfusion
& Blood Diseases
Erica Wood

Breast Device
Ingrid Hopper

Prostate Cancer
Sue Evans

Bariatic Surgery
Wendy Brown

Registry
Sciences Unit
Susannah Ahern

Cardiac &
Other Medical
Danny Liew

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

REGISTRY CUSTODIAN

Associate Professor
Sue Evans
Head, Clinical Registry Unit

REGISTRY CONTACT

Dr Aneta Kotevski
pcor@monash.edu
03 9903 0673

CLINICAL LEADERS

Associate Professor
Jeremy Millar
Radiation Oncology

Professor Mark Frydenberg
Urology

Professor Ian Davis
Medical Oncology

REGISTRY CUSTODIAN

Professor John Zalcberg

Lead Principal Investigator

REGISTRY CONTACT

Ms Jennifer Holland

jennifer.holland@monash.edu

03 9903 0323

CLINICAL LEADERS

Mr Dan Croagh

Hepatopancreatobiliary Surgery

Professor Wendy Brown

Oesophagogastric Surgery

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

REGISTRY CUSTODIAN
Professor John Zalcberg
Lead Principal Investigator

REGISTRY CONTACT
Ms Margaret Brand
margaret.brand@monash.edu
03 9903 0206

CLINICAL LEADER
Dr Rob Stirling
Respiratory Medicine

REGISTRY CUSTODIAN

Associate Professor
Sue Evans
Head, Clinical Registry Unit

REGISTRY CONTACT

Ms Melanie Evans
pcor-vic@monash.edu
03 9903 0245

CLINICAL LEADER

Associate Professor
Jeremy Millar
Radiation Oncology

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
Prostate Cancer Foundation of Australia
Victorian Department of Health.
Cancer Australia.
Department of Health and Ageing

Website

pcr.registry.org.au

REGISTRY CUSTODIAN

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

REGISTRY CONTACT

Ms Angela Brennan
angela.brennan@monash.edu
03 9903 0517

CLINICAL LEADERS

Associate Professor Andrew Ajani
Cardiology

Dr Stephen Duffy
Cardiology

Dr David Clark
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 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

REGISTRY CUSTODIAN

Professor Chris Reid

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

---

REGISTRY CONTACT

Dr Nupur Nag

nupur.nag@monash.edu

03 9903 0674

CLINICAL LEADERS

Mr Gilbert Shardey

ANZSCTS Database Program Chair

Mr Julian Smith

ANZSCTS President and Research Committee Chair

REGISTRY CUSTODIANS

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

REGISTRY CONTACT

Ms Angela Brennan
angela.brennan@monash.edu
03 9903 0517

CLINICAL LEADER

Associate Professor
Jeffrey Lefkovits
Cardiology

Victorian Cardiac Outcomes Registry (VCOR)

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.

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, Vctoria.

Website

vcor.org.au

REGISTRY CUSTODIANS

Professor Danny Liew

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

DEVICE/PROCEDURE REGISTRIES

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

REGISTRY CUSTODIAN

Dr Ingrid Hopper
Head, Drug and Device Registries

REGISTRY CONTACT

Ms Catherine Mulvany
abdr@monash.edu
03 9903 0205

CLINICAL LEADERS

Professor Rod Cooter
Past President Australian
Society of Plastic Surgeons

**Associate Professor
Colin Moore**
Foundation President,
Australasian College
of Cosmetic Surgery

Dr Elisabeth Elder
Chair Oncoplastic Subcommittee,
Breast Surgeons of Australia
and New Zealand Inc.

REGISTRY CUSTODIAN
Professor John McNeil
Head, School of Public Health
and Preventive Medicine

REGISTRY CONTACT
Ms Dianne Brown
med-bsr@monash.edu
03 9903 0725

CLINICAL LEADER
Professor Wendy Brown
Oesophagagostric Surgery

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

Obesity Surgery Society of Australia and New Zealand, Commonwealth Government, Department of Health. Industry Partners – Applied Medical, Medtronic and Gore.

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 CUSTODIAN

Professor
Rachelle Buchbinder
Director, Monash Department
of Clinical Epidemiology

REGISTRY CONTACT

Ms Vibhasha Chandi
arad@monash.edu
03 9508 1652

CLINICAL LEADERS

Professor Lyn March
Rheumatology

Professor Marissa Lassere
Rheumatology

Professor Catherine Hill
Rheumatology

REGISTRY CUSTODIAN
Professor John McNeil
Head, School of Public Health
and Preventive Medicine

REGISTRY CONTACT
Dr Leah Kivivali
sphpm-rokd@monash.edu
1800 811 326

CLINICAL LEADER
Professor Rowan Walker
Nephrology

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.

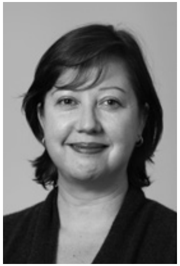
Funding source

Industry partners.

Website

rokd.org.au

TRANSFUSION AND BLOOD DISEASES



REGISTRY CUSTODIAN
Associate Professor
Erica Wood
Head, Transfusion Research Unit

REGISTRY CONTACT
Dr Leah Kivivali
aar@monash.edu
1800 811 326

CLINICAL LEADER
Professor Frank Firkin
Haematology

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, 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.

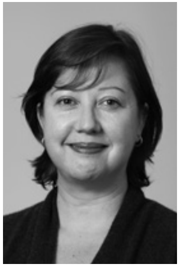
Long term outcomes are available through data linkages with death and other registries (i.e. death data).

Funding source

NHMRC partnership grant.

Website

torc.org.au



REGISTRY CUSTODIAN

Associate Professor
Erica Wood
Head, Transfusion Research Unit

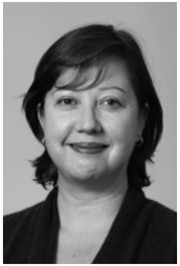
REGISTRY CONTACT

Dr Rasa Ruseckaite
sphpm.mtr@monash.edu
1800 811 326

CLINICAL LEADERS

Professor James Isbister
Hamatology

Dr Zoe McQuilten
Haematology



REGISTRY CUSTODIAN
Associate Professor
Erica Wood
Head, Transfusion Research Unit

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

CLINICAL LEADER
Professor Joy Ho
Haematology

Haemoglobinopathy Registry (HbR)

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

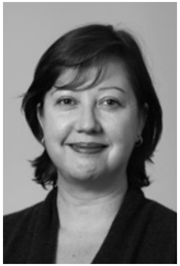
Adult patients with a new diagnosis of non-Hodgkin lymphoma, Hodgkin lymphoma, chronic lymphocytic leukaemia and related diseases in Australia and New Zealand.

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).

Funding source

Industry partners.



REGISTRY CUSTODIAN

Associate Professor
Erica Wood
Head, Transfusion Research Unit

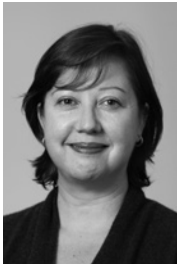
REGISTRY CONTACT

Dr Jessica Morison
sphpm-lymphoma@monash.edu
1800 811 326

CLINICAL LEADERS

Associate Professor
Stephen Opat
Hamatology

Dr Zoe McQuilten
Haematology



REGISTRY CUSTODIAN
Associate Professor
Erica Wood
Head, Transfusion Research Unit

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

CLINICAL LEADERS
Professor Andrew Spencer
Haematology

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

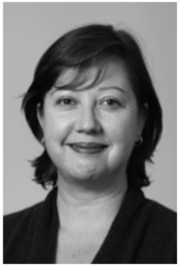
Demographics, diagnoses, clinical and laboratory and imaging results, therapy, complications of disease and therapy, transfusion, and support including intravenous immunoglobulin and platelet transfusions, and clinical outcomes.

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



REGISTRY CUSTODIAN

Associate Professor
Erica Wood
Head, Transfusion Research Unit

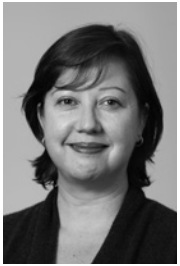
REGISTRY CONTACT

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

CLINICAL LEADERS

Dr Stephen Cole
Obstetrics

Dr Gemma Crighton
Paediatric Haematology



REGISTRY CUSTODIAN
Associate Professor
Erica Wood
Head, Transfusion Research Unit

REGISTRY CONTACT
Dr Leah Kivivali
med-ttpregistry@monash.edu
1800 811 326

CLINICAL LEADERS
Associate Professor
Shlomo Cohney
Nephrology

Dr Piers Blombery
Haematology

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


EMERGENCY
EMERGENCY
313
AMBULANCE

REGISTRY CUSTODIAN

Professor
Peter Cameron
Professor of Emergency and Divisional Head of Health Services Research

REGISTRY CONTACT

Ms Jane Ford
jane.ford@monash.edu
03 9903 0408

CLINICAL LEADERS

Professor
Peter Cameron
Emergency Medicine

Professor
Mark Fitzgerald
Emergency Medicine

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

REGISTRY CUSTODIAN

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

REGISTRY CONTACT

Ms Kylie Dyson
kylie.dyson@monash.edu
03 9903 0288

CLINICAL LEADER

Dr Heather Cleland
Victorian Adult Burns Service

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

REGISTRY CONTACT
Ms Melissa Hart
melissa.hart@monash.edu
03 9903 0113

CLINICAL LEADERS
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 (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

REGISTRY CUSTODIAN

Professor Belinda Gabbe

Head, Pre-Hospital, Emergency and Trauma Research Unit

REGISTRY CONTACT

Ms Mimi Morgan

mimi.morgan@monash.edu

03 9903 0996

CLINICAL LEADER

Professor Peter Cameron

Emergency Medicine

MONASH University

FURTHER INFORMATION

Registry Sciences Unit
Department of Epidemiology and Preventive Medicine
School of Public Health and Preventive Medicine
Monash University, 99 Commercial Road, Melbourne VIC 3004

T: +61 3 9903 0106
F: +61 3 9903 0556
E: med-clinicalregistries@monash.edu

CRICOS provider: Monash University 00008C.
Produced by Monash SMC. 16P-1138 September 2016