REGISTRY PROJECTS

Clinical registries are an effective tool to enable clinical benchmarking and inform quality improvement decisions. By collecting and analysing health data in a systematic way, they allow identification of variance in practice and clinical outcomes, as well as providing data for research.

Monash Public Health and Preventive Medicine is Australia’s largest provider of clinical registries. Our Transfusion Research unit manages several registries originally established under the auspices of the Transfusion Outcomes Research Collaborative (TORC), a partnership between the Australian Red Cross Blood Service and Monash University, and chaired by Associate Professor Merrole Cole-Sinclair.

These include the:

- **Massive Transfusion Registry**, a unique international collaboration with more than 5,000 cases of critical bleeding documented from many different clinical settings.

- **Aplastic Anaemia Registry**, an initiative now funded via Maddie Riewoldt’s Vision to capture information on children and adults with this disorder. We collaborate with the Melbourne Genomics Health Alliance to provide improved access to diagnostic genomic testing.

- **Thrombotic Thrombocytopenic Purpura (TTP)/Thrombotic Microangiopathies (TMA) Registry**, containing data on nearly 300 Australians with these conditions that whilst rare, are serious and have high plasma transfusion requirements.

- **Haemoglobinopathy Registry**, an expanding registry, providing the first national data on diagnosis and management of thalassaemia and sickle cell in Australia.

- **Neonatal Alloimmune Thrombocytopenia Registry**, gathering data on Australian women with this rare but serious condition associated with significant fetal and neonatal morbidity and mortality and requiring substantial, specialised transfusion support with platelets and immunoglobulins.

OVERVIEW

Monash Transfusion Research is an internationally recognised, multidisciplinary research team within Monash Public Health and Preventive Medicine.

We collaborate with clinical and institutional partners to lead national registries, clinical trials, systematic reviews, other projects and educational activities in a number of blood disorders and conditions requiring major or complex transfusion support.

Our work helps the medical and wider community better understand and improve clinical practice and outcomes. We provide data that informs health care policy and practice and contributes to high-quality patient care, improved patient outcomes and better stewardship of precious resources.

One in three Australians will need a blood transfusion. Our research drives safety, quality, efficiency and accessibility, and improves the quality of life of those living with blood disorders.

Driving quality and safety when they matter most

The Massive Transfusion Registry captures massive transfusion data across all clinical contexts from 25 hospitals in Australia and New Zealand. More than 5,000 cases have been analysed, with reports providing valuable insights to participating health services to support practice improvement. Data have been published in leading journals.

The registry is a cross-sector collaboration with clinicians and hospitals, and support from NHMRC, National Blood Authority, the Victorian Department of Health and Human Services, Australian Red Cross Blood Service, New Zealand Blood Service, CSL Behring, St John of God Pathology and Monash University.
We have significant expertise in managing clinical trials and are involved in multi-centre international studies. Our work helps identify best practice in transfusion here and around the world.

Our trials include:

- **TREATT**: Trial to evaluate anti-fibrinolytic therapy in thrombocytopenia, a collaborative RCT with NHS Blood and Transplant that explores the efficacy and safety of tranexamic acid to limit bleeding in people with haematologic malignancies and low platelet counts.

- **RATIONAL**: Role of antibiotic therapy or IVIg on infections in haematology, a National Blood Authority-funded trial ascertaining the safety and efficacy of oral antibiotics or intravenous immunoglobulin to reduce infection risk in adults with haematologic malignancies and low immunoglobulin levels. Data will inform a future large scale RCT.

- **REDDS pilot**: Red blood cell transfusion thresholds and QoL in myelodysplastic syndromes, laying important groundwork for a larger, randomised trial comparing haemoglobin thresholds for red cell transfusion in patients with transfusion-dependent myelodysplasia.

- **ITACS**: IV iron for treatment of anaemia before cardiac surgery, in collaboration with The Alfred, this is an international RCT comparing efficacy, safety and cost-effectiveness of preoperative intravenous iron in cardiac surgery patients with anaemia funded by the NHMRC and ANZCA.

- **Life-threatening massive obstetric haemorrhage requiring rapid, high-volume blood transfusion**, in collaboration with AMOSS, this is a prospective, population-based case control study across Australia and New Zealand investigating factors contributing to major obstetric haemorrhages and their management.

We also manage registries for other blood diseases, including:

- **Myeloma and Related Diseases Registry**, a rapidly expanding registry involving 35 hospitals that has collected data on 1,800 patients in under four years.

- **Lymphoma and Related Diseases Registry**, a novel pilot registry that began recruitment in 2016 and has already collected data on over 320 patients.

- **Venous Thromboembolism Cohort**, a registry containing data from over 400 Victorian thrombosis patients.

**Leading the world in myeloma registry science**

The Myeloma and Related Diseases Registry manages multiple sub-projects which will contribute to our understanding and treatment of these diseases.

The industry-funded M1000 bank is the world’s only prospective, fully annotated liquid biopsy biobank for myeloma and monoclonal gammopathies of undetermined significance. The registry also manages early-phase clinical trials, a study into outcomes and variation in immunoglobulin use, and a project evaluating real-time provision of patient-reported outcome measures.

Recent international collaborations are extending its impact into Asia and Europe.
**Evaluating best use of an effective, cost-saving drug to prevent bleeding**

TREATATT is the Australian arm of a multinational randomised trial exploring the use of an inexpensive antifibrinolytic agent, tranexamic acid, to prevent bleeding in individuals with low platelet counts due to haematologic malignancies. A collaboration with the NHS Blood and Transplant and University of Oxford, and funded by the NHMRC and ANZSBT, the project builds on our previous successful collaboration in the Trial of Prophylactic Platelets study in the same patient group (NEJM, 2013).

**OTHER PROJECTS**

We manage or contribute to a number of other projects. These include:

- **ASPREE Anaemia**, a sub-study of the largest primary prevention aspirin study ever undertaken in healthy older people. This study will help understand the causes and consequences of anaemia in the elderly.

- **Data linkage activities** with established large clinical registries (such as those involved with intensive care, cardiac surgery and trauma) and other major datasets, such as the Victorian Admitted Episodes Dataset and the National Death Index.

- **Health economic analyses** to help understand the real costs of transfusion, including the **True Cost of Transfusion in Thalassaemia** study.

- **Modelling studies** to understand the demand, availability and usage of blood products and the impact of emerging infections, such as Zika virus, on blood safety and availability.

- **Multiple systematic reviews** including exploring blood component ratios in massive transfusions, immunoglobulin and platelet use in haematologic malignancies, and reference ranges for the definition of anaemia.

**Research in immunoglobulin therapy and outcomes**

We are national leaders in clinical research exploring use and outcomes of immunoglobulin therapy. This includes three projects funded by the National Blood Authority: the **RATIONAL** study comparing oral antibiotics with immunoglobulin to prevent infections in haematologic malignancies; **IMPROVE**, a registry-based study of immunoglobulin use and infections in myeloma; and a national epidemiological study of Kawasaki Disease incidence and immunoglobulin therapy.

**COLLABORATION AND FUNDING**

Our group has an international reputation for transfusion and haematology research across many modes and this is reflected in our collaborations. We receive funding from or partner with prestigious groups such as the University of Oxford, NHS Blood and Transplant, NHMRC, National Blood Authority, the national blood services of Australia and New Zealand, colleges and societies including the Australian and New Zealand Society of Blood Transfusion, Australasian Myeloma Research Consortium, and the Australian Maternity Outcomes Surveillance System.

We also receive funding and support from community and patient groups such as Maddie Riewoldt’s Vision, Thalassaemia and Sickle Cell Australia, Thalassaemia NSW as well as government agencies and the pharmaceutical industry.

Our collaborations with internal Monash University groups including Epidemiological Modelling, Infectious Diseases, Registry Science and the Australian and New Zealand Intensive Care Research Centre expand our capacity and experience in relevant fields.

**EDUCATION AND TRAINING**

We offer opportunities for medical specialists in training, students and future researchers to develop solid foundations in research methodologies relevant to transfusion medicine and haematology. We also host and participate in a range of educational and professional meetings to share important new research findings with a broad audience.
PARTNERS, FUNDERS AND COLLABORATORS

We work with clinicians, scientists and institutions in Australia, New Zealand and internationally, including:

- Alfred Health Research Trusts
- Australasian Maternity Outcomes Surveillance System
- Australian Red Cross Blood Service
- Australian Centre for Blood Diseases
- Aust/NZ Society of Cardiac and Thoracic Surgeons
- ANZIC Research Centre
- Australasian Leukaemia and Lymphoma Group
- Australasian Myeloma Research Consortium
- Australian and NZ Society of Blood Transfusion
- Cancer Council Victoria, Victorian Cancer Registry
- Department of Health and Human Services Victoria
- Haematology Society of Australia and New Zealand
- Maddie Riewoldt’s Vision Foundation
- Myeloma Foundation Australia
- NHMRC
- National Blood Authority
- New Zealand Blood Service
- NHS Blood and Transplant and Systematic Review Initiative, UK
- Thalassaemia Australia, Thalassaemia Society NSW
- Thalassaemia International Federation
- Industry: Abbvie, Alexion, Amgen, Bayer, Bristol-Myers Squibb, Celgene, CSL, Gilead, Janssen, Novartis, Roche, Sanofi, Takeda

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