

MRDR Sites and Local Investigators

(italics = governance approval pending)

Adelaide Cancer Centre: Stanley Cheung
 Adelaide Oncology and Haematology: Wilfrid Jaksic
 Alfred Hospital: Andrew Spencer
 Austin Hospital: Andrew Lim
 Bairnsdale Regional Health Service: Amanda Ormerod
 Bendigo Hospital: Robert Blum
 Box Hill Hospital: Jay Hocking
 Cabrini Hospital: Gaurav Srivastava
 Calvary Mater Newcastle: Wojt Janowski
 Canberra Hospital: James D'Rozario
 Central Gippsland Health Service: Amanda Ormerod
 Christchurch Hospital: Ruth Spearing
 Concord Hospital: Jane Estell
 Dunedin Hospital: Ian Morison
 Epworth Freemasons Hospital: Miles Prince
 Fiona Stanley Hospital: Dustin Hall
 Flinders Medical Centre: Magdalena Sobieraj-Teague
 Frankston Hospital: Patricia Walker
 Geelong Hospital: Philip Campbell
 Hollywood Private Hospital: Bradley Augustson
 ICON Cancer Care: Kerry Taylor
 Jarrett St Specialist Centre, Gosford: Cecily Forsyth
 Lake Macquarie Private Hospital: Wojt Janowski
 Latrobe Regional Hospital: Tricia Wright
 Lismore Hospital: Louise Imlay
 Liverpool Hospital: Sylvia Ling
 Middlemore Hospital: Hilary Blacklock
 Monash Medical Centre: George Grigoriadis
 Nelson Hospital: Luke Merriman
 Nepean Cancer Centre: Anita Shetty
 Northern Hospital: Teresa Leung
 Northland Hospital: Sarah Poplar
 North Shore Hospital: David Simpson
 Peter Mac / Royal Melbourne: Michael Dickinson
 Princess Alexandra Hospital: Peter Mollee
 Royal Brisbane and Women's Hospital: Jason Butler
 Royal Darwin Hospital: Akash Kalra
 Royal Hobart Hospital: Anna Johnston
 Royal North Shore Hospital: Ian Kerridge
 Royal Prince Alfred Hospital: P Joy Ho
 Sir Charles Gairdner Hospital: Bradley Augustson
 St George Hospital: Sundra Ramanathan
 St Vincent's Hospital, Melbourne: Hang Quach
 St Vincent's Hospital, Sydney: Nada Hamad
 Sunshine Hospital: William Renwick
 Sunshine Coast University Hospital: Anthony Powell
 Toowoomba Hospital: Howard Mutsaers
 Townsville Hospital: Georgina Hodges
 Wellington Hospital: Anup George
 Whangarei Hospital: Sarah Poplar

MRDR Steering Committee

Prof Andrew Spencer: Alfred Hospital / Monash
 Dr Bradley Augustson: Sir Charles Gairdner Hospital
 Dr Krystal Bergin: Alfred Hospital / Monash
 Dr Hilary Blacklock: Middlemore Hospital, NZ
 A/Prof Simon Harrison: Peter MacCallum Cancer Centre / Royal Melbourne Hospital
 Prof Joy Ho: Royal Prince Alfred Hospital
 Dr Noemi Horvath: Royal Adelaide Hospital
 Ms Tracy King: Royal Prince Alfred Hospital
 Prof John McNeil: Monash University
 A/Prof Zoe McQuilten: Monash University
 A/Prof Peter Mollee: Princess Alexandra Hospital
 A/Prof Hang Quach: St Vincent's Hospital
 Prof Chris Reid: Monash University
 Mr Brian Rosengarten: Myeloma Australia
 Dr Patricia Walker: Frankston Hospital
 Prof Erica Wood: Monash University

MRDR Team Members

Coordinating Principal Investigator: Prof Andrew Spencer
 - The Alfred Hospital & Monash University
 Administration: Transfusion Research Unit (TRU),
 Monash University
 Head of TRU: Prof Erica Wood
 Associate Investigator: A/Prof Zoe McQuilten
 Research Fellow/Project Manager: Dr Liz Moore
 Data Manager: Dr Cameron Wellard
 PhD student / Haematologist: Dr Krystal Bergin
 Senior Projects Officer: Mr Neil Waters
 Research Officer: Dr Laura Sellick
 APAC-MRDR Project Manager: Ms Naomi Aoki
 Project Officer (AMARC): Mr James Wilkie

Congratulations! MRDR achievements 2018

Reached **2504** patients registered



704 New patients registered

- 39% increase on Dec 2017 accrual



50 Hospitals & clinics

- 43% increase on Dec 2017
- 38 approved
- 12 pending approval



12 Requests: data/analyses

- 8 investigator driven
- 4 industry



297 Myeloma 1000 biobank patients accrued



Welcome to the MRDR annual report! 2018 was a year of exceptional growth for the registry and we look forward to continuing the momentum in 2019.

MRDR activities

Participation: Recruitment reached over 2500 in December 2018, with 69% multiple myeloma (MM), 25% monoclonal gammopathy of undetermined significance (MGUS), and 5% smouldering MM patients (1% other related diseases) recruited from 31 of the 38 approved hospital sites. Twelve new sites have approval pending.

Presentations: The MRDR team made presentations at key scientific and clinical meetings during 2018 including the European Society for Blood and Marrow Transplantation, Australian National Myeloma Workshop, and Blood 2018. Presentations addressed diagnostics and treatment, early mortality, renal impairment, use of autologous stem cell transplant (ASCT), and quality of life (QoL) at diagnosis in MM (see details on our website under Outputs: mrd.net.au). Several manuscripts are being prepared for publication.

Myeloma 1000 Project

The Myeloma 1000 biobank project reached almost 300 participants (49% MM, 46% MGUS, 5% SMM) with close to 100 patients recruited in 2018. There are now 11 approved sites and a further 5 with approval pending. We look forward to 2019 being another year of record recruitment towards our goal of having samples from 1000 MM and 1000 MGUS patients in the biobank.



Blood is taken at sites, sent to the Alfred Hospital campus, processed then freeze-stored

IMPROVE (Immunoglobulins in myeloma patients: research into outcomes, variation in practice and epidemiology)

IMPROVE is a sub-study of the MRDR. Funded by the National Blood Authority, this study aims to investigate infections and immunoglobulin (Ig) use in patients with MM in Australia, and provide information to improve national Ig stewardship and patient outcomes. Data is entered at baseline and 4 follow-up timepoints. The study offers a per patient payment and for participation in the IMPROVE biobank study. IMPROVE has 30% of patients identified at the initial sites and is opening more sites during 2019.

My-PROMPT

My-PROMPT is a multicentre pilot randomised trial to test the feasibility of real-time reporting of patient-reported outcomes to clinicians treating patients with MM. Target recruitment was reached in October with 32 patients and follow-up will be complete in May 2019. Takeda and Gilead fund this study.

Asia-Pacific expansion of MRDR (APAC-MRDR)

APAC-MRDR was established in 2018 to monitor the differences in access to and patterns of care and their outcomes in patients across multiple countries in the APAC region. The APAC registry operates in parallel to the MRDR, with its own steering committee and country specific databases. APAC-MRDR had a busy and productive first year with seven hospitals obtaining ethics approval to participate. Korea and Singapore have active sites with 65 patients registered, with Taiwan and Hong Kong to follow. The International Steering Committee met at ASH in 2018 and the first country Investigator's Meeting is planned for 2019. Janssen funds this project.



Other international activities

Myeloma UK, a patient advocacy group, exploring establishment of a UK Myeloma registry contacted the MRDR team to discuss our experience with the MRDR. Of the groups interviewed internationally, they found the MRDR to be one of the best examples of a model registry for myeloma and haematological diseases, and have invited us to participate in a follow-up stakeholder workshop. A great endorsement for the registry!



Dr Donna Reece, Director of the **Myeloma Canada Research Network (MCRN)** met with MRDR leads Prof Andrew Spencer and Prof Erica Wood in 2018. Subsequently, at ASH in San Diego, Erica and A/Prof Zoe McQuilten presented the MRDR to the MCRN and a number of interesting opportunities for further collaboration were identified.

A link with the **Danish Myeloma Registry (DMR)** has been established following a meeting at University of Sydney in July, with presentations on both the DMR and MRDR, providing the opportunity for future collaboration.

Australasian Myeloma Research Consortium (AMARC)

AMARC is a group of doctors and scientists who have come together to develop and run early-phase clinical trials quickly and safely. This includes organising and overseeing ethics approval, contracts, documentation, patient safety and compliance with regulations. AMARC operational staff and partner organisations, such as the Alfred Hospital Haematology Clinical Research Unit, offer expertise and experience in running clinical trials, to ensure they are conducted efficiently and within reasonable timeframes. AMARC uses the MRDR's infrastructure and established national network of sites to conduct clinical trials and long-term follow-up. Currently, **recruitment to 6 AMARC trials** is underway, incorporating novel agents such as venetoclax, daratumumab, KappaMab and isatuximab. This also includes **FRAIL-M**, a study that will be conducted to identify which treatments are more appropriate in transplant-ineligible myeloma patients according to frailty status. More information is available on the AMARC website: www.amarconline.org



MRDR at Blood 2018 in Brisbane

The annual MRDR interest group breakfast meeting was held at Blood 2018 in October with 61 attendees representing patient groups, clinicians, researchers, hospitals, industry, and other collaborators. Attendees enjoyed an update on progress from the MRDR and associated projects.

The MRDR was also well represented in the conference program with 3 oral presentations and one poster, including an overview



of the MRDR and data on early mortality, ASCT, and QoL at diagnosis. Dr Krystal Bergin was nominated for the Outstanding Young Investigator award for her abstract on ASCT in MM, and Dr Elizabeth Moore was awarded the Snowdome Foundation Haematology Nurse Myeloma Travel Grant for a poster on QoL at diagnosis in MM. We also provided MRDR data for Dr Kylee Maclachlan's oral presentation on use of imaging in MM.

Thank you

Thank you to our steering committee and participating individuals and sites for your hard work and enthusiasm – the MRDR depends on you for its continued progress! We also thank our funding partners for 2018: Amgen Inc., Celgene Pty Ltd, Gilead Sciences Pty Ltd, Janssen-Cilag Pty Ltd, Medical Research Future Fund, Monash Partners Advanced Health Research Translation Centre, National Blood Authority, and Takeda Pharmaceuticals Australia Pty Ltd. We appreciate your support and look forward to a very productive 2019.

To contact the MRDR:

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