

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
 Border Medical and Oncology: Anish Puliyaail
 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
 Lyell McEwen Hospital: Stanley Cheung
 Middlemore Hospital: Hilary Blacklock
 Monash Medical Centre: George Grigoriadis
 Nelson Hospital: Luke Merriman
 Nepean Cancer Centre: Anita Shetty
 Northern Hospital: Rachel Cooke
 Northland Hospital: Sarah Poplar
 North Shore Hospital: David Simpson
 Orange Hospital: Charmaine Wong
 Perth Blood Institute: Maan Alwan
 Peter Mac / Royal Melbourne: Simon Harrison
 Princess Alexandra Hospital: Peter Mollee
 Royal Brisbane and Women's Hospital: Jason Butler
 Royal Darwin Hospital: Tina Noutsos
 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 Mutsando
 Townsville Hospital: Georgina Hodges
 Wellington Hospital: Anup George
 Whangarei Hospital: Sarah Poplar

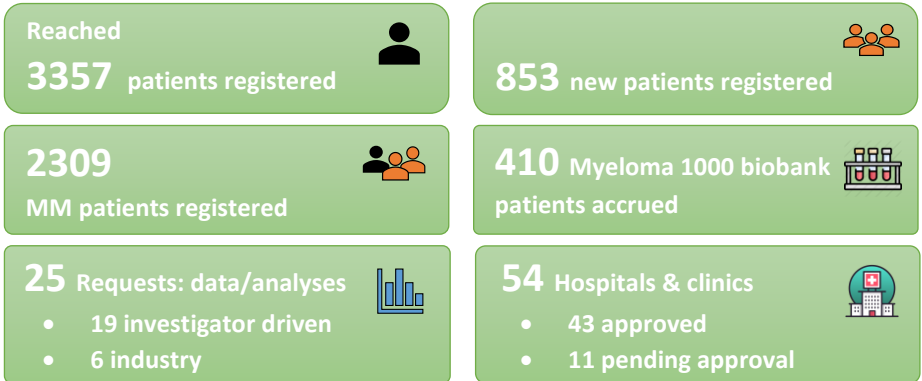
MRDR Steering Committee

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): Ms Christine Quek

MRDR achievements 2019 – thanks to all participating sites!



Welcome to the MRDR annual report! 2019 marked a year of increasing research growth and record recruitment for the registry, and we expect a bright and fruitful year ahead.

MRDR activities

Participation: Recruitment reached over 3300 during 2019 with the inclusion of multiple new sites; 69% were patients with multiple myeloma (MM), and 30% had monoclonal gammopathy of undetermined significance (MGUS) or smouldering MM (1% were other related diseases) from 37 of the 43 approved hospital sites. Eleven sites were pending governance approval at the end of 2019.

Presentations: The MRDR was well represented at conferences and meetings locally and internationally in 2019, with multiple presentations at the [International Myeloma Workshop \(IMW\) in Boston](#), attended by over 3200 delegates, and [Blood 2019 in Perth](#).



Presentation topics included the influence of Polynesian ethnicity on diagnosis, treatment and outcomes in New Zealand (A/Prof Hilary Blacklock); the impact of number of cycles of therapy on outcomes in patients treated with bortezomib induction (A/Prof Peter Mollee); and results of My-PROMPT, a pilot randomised controlled trial to test the feasibility of real-time feedback of patient-reported outcomes to clinicians treating patients with MM (Dr Elizabeth Moore). MRDR

team member, Dr Jessie Zhao (see image), was awarded the Snowdome Foundation Haematology Clinician Travel Grant for her presentation on treatment patterns and sequencing in MM. At [ASH in Orlando, USA](#), Prof Spencer presented on outcomes for MRDR patients with MM and early progression or sub-optimal response to treatment.

Website: The MRDR website has been revamped with a more open plan, recent news items, and a current list of registry projects. The URL remains the same (mrd.net.au).

Projects: Several new investigator-initiated analyses using MRDR data or infrastructure are at different stages of development including: timing of treatment and outcomes of patients with biochemical relapse in MM; use of bortezomib-based therapy in non-transplant eligible MM; comparison of characteristics and outcomes of patients diagnosed with MM by traditional CRAB criteria versus 'newer' biomarkers of malignancy; and regional outcomes in MM. Investigators involved in projects can range from experienced clinical researchers to nurses and registrars working on their first research project. See the MRDR website for a project list. We welcome enquiries and proposals for projects using registry data.



Engaging with collaborators

The 7th annual MRDR Interest Group breakfast was held at Blood 2019 in Perth. Dr Brad Augustson, MRDR Steering Committee member and principal investigator from Sir Charles Gairdner Hospital in Perth gave an update on registry data and progress to over 60 attendees representing patient groups, hospitals, researchers, industry, and other



collaborators (see image). Later, Tracy King, Myeloma Clinical Nurse Consultant at Royal Prince Alfred Hospital and MRDR steering committee member presented on how MRDR data reports could be used to improve care. The registry was also represented at Monash University's Transfusion Research Unit booth in the exhibition area at Blood to promote the MRDR.

Myeloma 1000 Project

The Myeloma 1000 biobank project has accrued 410 participants (54% MM, 41% MGUS, 5% SMM), with 113 patients recruited in 2019. There are now 11 approved sites and a further 7 pending approval. Transport times by Express Post from interstate sites to specimen reception at the Alfred Hospital are satisfactory. We welcome the participation of new Australian sites - see contact details below. The first research proposals with biobank requests were received in 2019, and samples have been sent to researchers from the University of Adelaide for a project investigating whether serum CTX-1 levels predict progression from pre-malignancy to active disease in MM.

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. It aims to investigate infections and immunoglobulin (Ig) use in patients with MM in Australia and New Zealand, and provide information to improve national Ig stewardship and patient outcomes. Data is entered at baseline and 4 follow-up time points. The study offers a per-patient payment for data collection (\$500) and for participation in the IMPROVE biobank study (+\$200). The IMPROVE biobank is seeking more Victorian sites interested in participating.

My-PROMPT

My-PROMPT is a multicentre pilot randomised controlled trial to test the feasibility of real-time feedback of PRO to clinicians treating patients with MM. The pilot trial is complete, results have been presented, and the manuscript is in the process of submission for publication with qualitative interview results incorporated. We are now seeking funding for a follow-up study. Thanks to participating patients and sites for your help with the trial. Takeda and Gilead funded this study.

International

In April 2019, Myeloma UK invited MRDR to present at their Stakeholder Registry Workshop in London. The meeting was to help them determine patient and industry needs in the establishment of their registry. Feedback was positive. The German-based International Multiple Myeloma rESEarch (IMMEnSE) biobank consortium invited the Myeloma 1000 biobank to participate. Consortium focus is on genetic susceptibility to MM and its characterization. MRDR steering committee approved.

Asia-Pacific expansion of MRDR (APAC MRDR)

APAC MRDR was established in 2018 to monitor differences in access to and patterns of care and outcomes in patients across countries in the APAC region. It operates in parallel to the ANZ MRDR, and has a separate steering committee and country-specific databases. The Registry currently has hospitals in Korea, Malaysia and Singapore enrolling participants with 334 enrolled so far. The inaugural APAC MRDR Investigators' Meeting was held during the International Myeloma Workshop (IMW) in Boston, USA; it was well attended by investigators from Australia,



Korea, China, Hong Kong, Taiwan, and Singapore (see image). Throughout 2020, the APAC MRDR will invite additional hospitals and countries to participate, closely monitor current sites and data to ensure data completeness and accuracy, and circulate the next Hospital Data Reports to contributing hospitals. Janssen funds this project.

Australasian Myeloma Research Consortium (AMARC)

AMaRC is a group of clinicians and scientists who develop and conduct investigator-led trials quickly and safely. With a network of research specialists, AMaRC aims to develop, set up and trial early phase, and proof-of-concept treatment regimes, biologics and drug products in sites in Australia and New Zealand. AMaRC can take care of trial administration including ethics approval, contracts, documentation, and patient safety and compliance procedures. Within 3 years of commencing operations, AMaRC has completed 3 studies involving novel therapeutic agents KappaMab, Venetoclax and Daratumumab. AMaRC has valued partnerships with the pharmaceutical industry, the Myeloma Research Group laboratory, the Haematology Clinical Research Unit at the Alfred Hospital; collaborative research groups such as ALLG, and patient advocacy groups such as Myeloma Australia. AMaRC benefits from use of the MRDR's established infrastructure and national site network as a platform for trials in newly diagnosed MM and seeks collaborators and partners to develop novel clinical trials in MM. For more information: AMaRC website: www.amarconline.org and twitter account @MyelomaAmarc: <https://twitter.com/myelomaamarc>



Thank you to our steering committee and participating individuals and sites – we appreciate all your work - the MRDR depends on you for its continued progress! We also thank our funding partners for 2019: Amgen, Celgene, Gilead, Janssen, Sanofi, Takeda, Medical Research Future Fund, Monash Partners Advanced Health Research Translation Centre, and National Blood Authority. We appreciate your support and look forward to a very productive 2020.

To contact the MRDR: Website: mrd.net.au Email: sphpm-myeloma@monash.edu Phone: 1800 811326