

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: Emma-Jane McDonald
 Concord Hospital: Jane Estell
Cooks Hill Private Practice: Wojt Janowski
 Dunedin Hospital: Ian Morison
 Epworth Freemasons Hospital: Miles Prince
Fiona Stanley Hospital: Dustin Hall
 Flinders Medical Centre: Craig Wallington-Beddoe
 Frankston Hospital: Patricia Walker
 Geelong Hospital: Philip Campbell
Griffith Hospital: Nada Hamad
 Hollywood Private Hospital: Bradley Augustson
 ICON Cancer Care: Kerry Taylor
 Jarrett St Specialist Centre, Gosford: Cecily Forsyth
John Flynn Private Hospital: Shane Bleakley
 Latrobe Regional Hospital: Tricia Wright
 Launceston General Hospital: Jessica Heenan
 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
North Shore Hospital: Henry Chan
 Orange Health Service: Charmaine Wong
 Palmerston North Hospital: Bart Baker
Perth Blood Institute: Maan Alan
 Peter Mac / Royal Melbourne: Simon Harrison
Pindara Private Hospital: Hanlon Sia
Port Macquarie Hospital: Jock Simpson
 Princess Alexandra Hospital: Peter Mollee
 Royal Adelaide Hospital: Noemi Horvath
 Royal Brisbane & Women's Hospital: Nicholas Weber
 Royal Darwin Hospital: Tina Noutsos
 Royal Hobart Hospital: Nick Murphy
 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
 Tamworth Hospital: Israfil Baluwala
 Toowoomba Hospital: Howard Mutsando
 Townsville Hospital: Georgina Hodges
Tweed Hospital: Alejandro Arbelaez
Wagga Wagga Hospital: Nada Hamad
 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
 A/Prof Hilary Blacklock: Middlemore Hospital, NZ
 A/Prof Simon Harrison: Peter Mac/Royal Melbourne
 Prof Joy Ho: Royal Prince Alfred Hospital
 Dr Noemi Horvath: Royal Adelaide Hospital
 Ms Tracy King: Royal Prince Alfred Hospital
 A/Prof Zoe McQuilten: Monash University
 A/Prof Peter Mollee: Princess Alexandra Hospital
 A/Prof Hang Quach: St Vincent's Hospital, Melbourne
 Mr Brian Rosengarten: Myeloma Australia
 Dr Patricia Walker: Frankston Hospital
 Prof Erica Wood: Monash University

MRDR Team Members

Coordinating Principal Investigator: Prof Andrew Spencer
 Administration: Transfusion Research Unit (TRU), Monash
 Head of TRU: Prof Erica Wood
 Associate Investigator: A/Prof Zoe McQuilten
 Research Fellow/Project Manager: Dr Elizabeth Moore
 Data Manager: Dr Cameron Wellard
 PhD student / Haematologist: Dr Krystal Bergin
 Senior Projects Officer: Mr Neil Waters
 Research Officer: Ms Sabine Albold
 APAC-MRDR Project Manager: Ms Naomi Aoki
 Business Development Project Manager (AMARC): Mr Khoa Le

MRDR achievements 2020 – thanks to all participating sites!
 2020 was a challenging year but thanks to your wonderful work
 MRDR made significant progress.

MRDR reached:



4182 patients registered



825 new patients



~2960 MM patients registered



501 Myeloma 1000 biobank patients



63 hospitals & clinics

- 51 approved
- 12 pending approval



36 Requests: data/analyses/projects

- 26 investigator driven
- 10 industry

We are pleased to share with you this report on MRDR activities and progress over 2020, a year of continued growth and development, and we look forward to another busy and productive year ahead!

MRDR activities

Participation: Recruitment reached over 4000 during 2020; 71% were patients with multiple myeloma (MM), 27.5% had monoclonal gammopathy of undetermined significance (MGUS) or smouldering MM, and 1.5% had other related diseases. Eight new sites were approved, and patients were recruited from 45 of the 51 approved hospital sites. Twelve sites were pending governance approval at the end of the year.

Presentations: The MRDR was well-represented at the virtual **3rd National Myeloma Workshop (NMW)** with 5 presentations, and was also present at international meetings: **EHA Virtual Congress** and **ASH**. Topics included a comparison of patients diagnosed with MM by the biomarker criteria, versus CRAB criteria (Prof Joy Ho: ASH), a description of the myeloma landscape in Australia (Dr Krystal Bergin: EHA), and a look at early progression as a marker of high risk in newly diagnosed MM (Prof Andrew Spencer: NMW). Further NMW presentations looked at causes of death in MM (Ms Rosalyn Cao), patients with non-transplant eligible MM treated with bortezomib versus lenalidomide (Ms Natthida Khajornjiraphan), and outcomes in patients with multiple cytogenetic abnormalities at diagnosis (Dr Alannah Jackson / Dr Brad Augustson).

Publications: Findings of the My-PROMPT multicentre pilot trial were published in 2020: <https://onlinelibrary.wiley.com/doi/full/10.1002/ajh.25815>; confirming the feasibility and acceptability for patients and clinicians of real-time reporting of PROMs to clinicians, and supporting the viability of a larger trial in this area. We are seeking funding for a follow-up project. A descriptive paper by Dr Krystal Bergin on real world MM in the MRDR was accepted for publication in 2020, and published in January 2021: [https://www.clinical-lymphoma-myeloma-leukemia.com/article/S2152-2650\(21\)00034-3/fulltext](https://www.clinical-lymphoma-myeloma-leukemia.com/article/S2152-2650(21)00034-3/fulltext).

Database changes: The MRDR is incorporating the diagnosis of AL amyloidosis (ALA). Preparation for this has been underway for some time and we are pleased to announce that this has now gone live. As the ALA data matures we look forward to the benefits that its inclusion in a clinical quality registry affords for patients with this diagnosis.

Projects: Several new investigator-initiated analyses using MRDR data or infrastructure are at different stages of development including *the impact of daratumumab on real-world outcomes in MM*, and *myeloma outcomes based on socio-economic status*. See the MRDR website for a complete list. We welcome enquiries and proposals for further projects. Investigators can range from experienced clinical researchers to nurses and registrars working on their first research project.



Engaging with collaborators

The 8th annual MRDR Interest Group meeting was held as part of the virtual National Myeloma Workshop hosted by Myeloma Australia in September 2020. This was attended by a record 121 attendees including clinicians, researchers, site staff and industry representatives. The program included a presentation on the participation of regional sites in the MRDR by Dr Cecily Forsyth and the introduction of an epidemiological modelling project (EpiMAP Myeloma) to improve delivery of care in the future, by A/Prof Dennis Petrie. Thanks to Myeloma Australia for their support.



Speaker panel via Zoom at MRDR meeting

Myeloma 1000 Project

The Myeloma 1000 biobank project has accrued over 500 participants (56% MM, 33% MGUS, 11% SMM), with 91 patients recruited in 2020. We now have 11 approved sites and 7 more pending approval. We welcome the participation of new Australian sites - see contact details below. The first biobank requests for research proposals received in 2019 have been sent through to researchers who report they are making good progress.

EpiMAP Myeloma



The MRDR-based EpiMAP Myeloma project lead by A/Prof Zoe McQuilten received MRFF funding in 2020 to determine the projected numbers of patients likely to require different stages of treatment over the next 5 years. This will facilitate planning for and evaluation of new, high-cost therapies. The project is well underway; staff have been appointed, project approvals obtained and work is in progress.

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

The National Blood Authority-funded IMPROVE study reached target recruitment of 300 patients in 2020 and data analysis has commenced in 2021. This MRDR sub-study collecting data in Australia and New Zealand on immunoglobulin use and its administration in MM in response to infection, will shed light on current practice, costs and outcomes in the use of this high-cost resource. Immunoglobulin use is increasing and there is much variation in practice; IMPROVE aims to guide policy and clinical practice to improve the stewardship of this resource in Australia. The IMPROVE biobank is seeking more Victorian sites interested in participating; please contact us if you are interested.

APAC MRDR

This sister registry to the MRDR in the Asia-Pacific region currently has 16 hospitals in Korea, Malaysia and Singapore enrolling participants, with 638 patients so far - Taiwan is soon to follow. The APAC MRDR team was very pleased with the approval of a further \$5.3 million from Janssen-Cilag Pty Ltd to support the continuation of the APAC MRDR as well as the expansion into additional hospitals and also the fifth country, China. We look forward to the ongoing growth of the APAC MRDR and the potential for future collaborations with the MRDR.



Australasian Myeloma Research Consortium (AMARC)



AMaRC is a not-for-profit myeloma clinical trial research group associated with the MRDR, composed of clinicians and scientists who develop and conduct investigator-led early phase proof-of-concept studies, trialing novel drug and biologic products in Australia and New Zealand. They can manage all trial activities including ethics approval, contracts, protocol development, recruitment, patient safety, compliance, writing and publication. AMaRC have completed 4 trials, and have 3 in progress with more to come in 2021. They have experience with novel agents including KappaMab, Venetoclax, Daratumumab, Isatuximab, Belantamab and Ixazomib, and have valued partnerships with the pharmaceutical industry, the Myeloma Research Group laboratory, the Alfred Haematology Clinical Research Unit, ALLG and Myeloma Australia. AMaRC leverages the MRDR's established infrastructure and national site network as a platform for trials in MM and seeks collaborators and partners to develop novel clinical trials in MM. AMaRC Website: www.amarconline.org; Email: amarc@alfred.org.au; Twitter: @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 2020: Amgen, AbbVie, Celgene/BMS, Janssen, Sanofi, Medical Research Future Fund, Monash Partners Advanced Health Research Translation Centre, and the National Blood Authority. We appreciate your support and look forward to a very productive 2021.

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