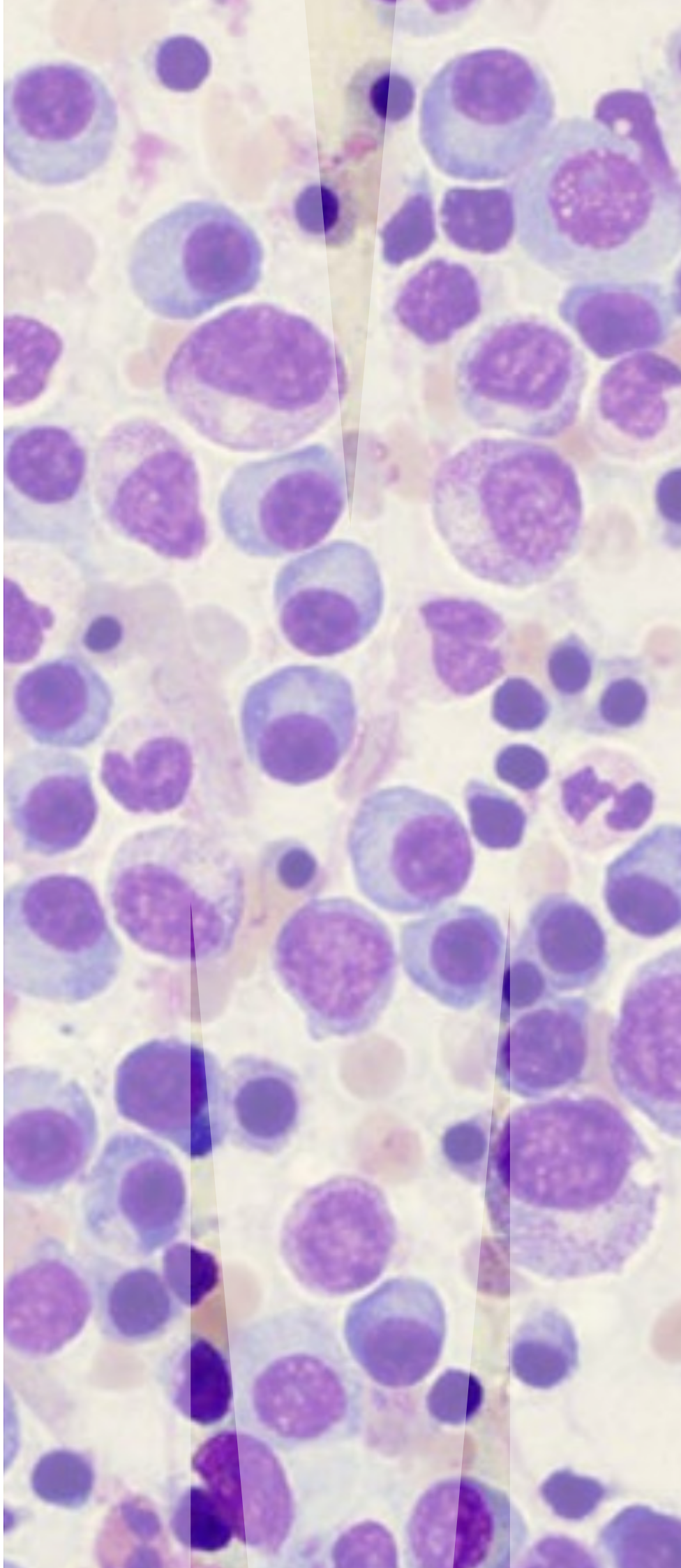


# MYELOMA AND RELATED DISEASES REGISTRY (MRDR)

2021 ANNUAL REPORT



The MRDR is a clinical quality registry established in 2012 that aims to improve myeloma outcomes by providing an evidence base for the best strategies to diagnose, treat and support people with myeloma and related diseases.

The registry has participating hospitals and clinics in all jurisdictions in Australia and New Zealand. Data collected includes patient demographics, clinical characteristics, test results at diagnosis, treatment, response, follow-up and outcomes including survival and quality of life.

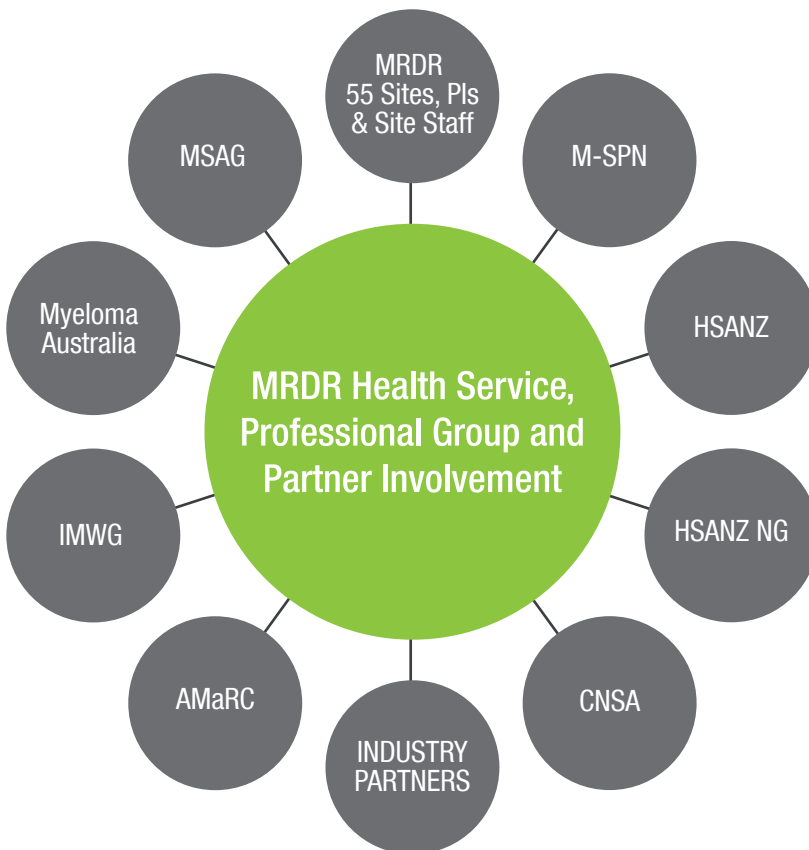
## BENCHMARKING TO IMPROVE CARE

The MRDR provides six-monthly data reports to participating sites comparing each site's registry data to the rest of the MRDR cohort. Treatment varies between centres, and these reports allow treating institutes and clinicians to identify areas of difference and where there may be opportunities for improvement. In this way the MRDR facilitates work towards higher quality care.

## MRDR NETWORK

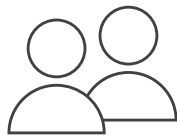
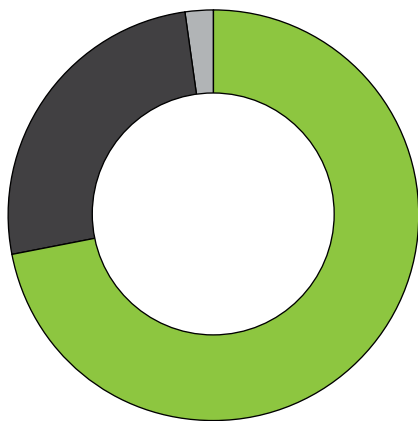
The established MRDR network and data collection infrastructure of >50 participating metropolitan & regional, public & private health services throughout Australia and New Zealand provides a solid base from which to conduct many and diverse projects, and enhances our capacity for rapid translation of results. In addition, the MRDR's close association with relevant professional and research groups, Myeloma Australia (a national patient advocacy group), policy-makers and industry partners, further strengthens our capacity for research translation.

The MRDR informs national and international policy, guidelines and practice through representation of Management and Steering Committee members in:



- Myeloma Australia
- Myeloma Australia Medical Scientific Advisory Group (MSAG)
- Haematology Society of ANZ Nursing Group (HSANZ NG)
- Myeloma Special Practice Network (M-SPN) of the HSANZ NG
- Haematology Society of ANZ (HSANZ)
- Cancer Nurses Society of Australia (CNSA)
- International Myeloma Working Group (IMWG)
- Australasian Myeloma Research Consortium (AMaRC)
- Synergistic relationship with pharmaceutical industry partners

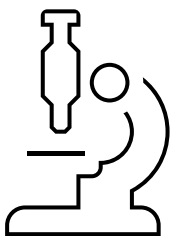
# MRDR 2021 AT A GLANCE



## 5033 PATIENTS REGISTERED

852 NEW PATIENTS

- 72% MULTIPLE MYELOMA (MM)
- 26% MGUS / SMOULDERING MM<sup>1</sup>
- 2% PCL<sup>2</sup> / PLASMACYTOMA



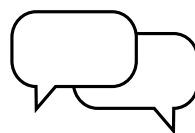
## MYELOMA 1000 BIOBANK: THE ONLY PROSPECTIVE FULLY ANNOTATED 'LIQUID BIOPSY' BIOBANK IN THE WORLD

560 MYELOMA 1000 BIOBANK PATIENTS:



- 59% MM
- 32% MGUS
- 9% SMM

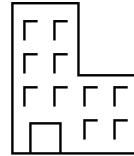
15 MYELOMA 1000 APPROVED SITES



## 38 REQUESTS: DATA/ANALYSES/REPORTS

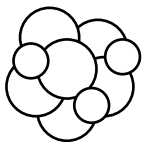
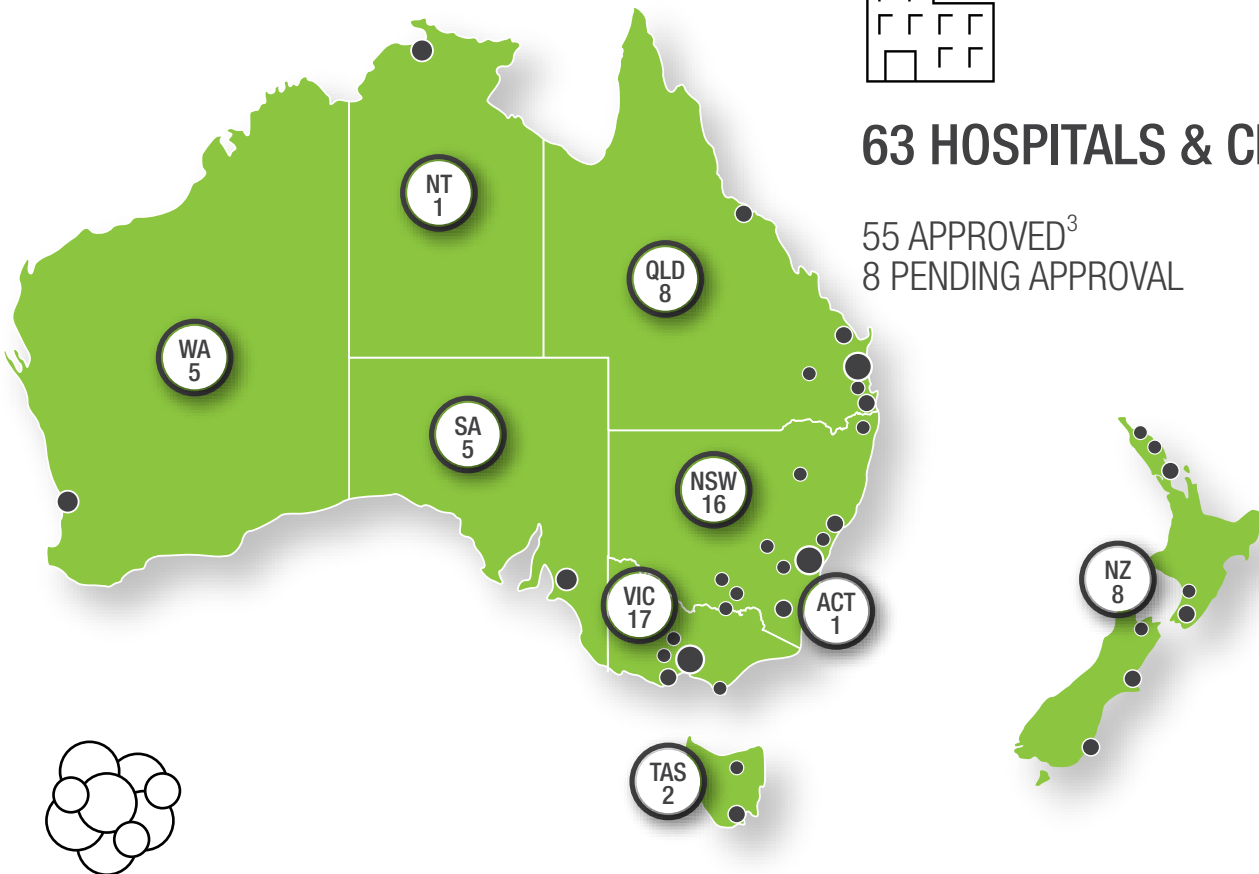


- 23 INVESTIGATOR-DRIVEN
- 9 OPERATIONAL / ONGOING REPORTS
- 6 INDUSTRY



## 63 HOSPITALS & CLINICS

55 APPROVED<sup>3</sup>  
8 PENDING APPROVAL



## MULTIPLE MYELOMA

### PATIENTS

AGE (MEDIAN): 68 YEARS  
FEMALE 40% / MALE 60%

### SURVIVAL

56% OF PATIENTS SURVIVE  
TO 5 YEARS

### STEM CELL TRANSPLANTS IN PATIENTS <70 YEARS<sup>4</sup>

ALL PATIENTS: 75%  
<65 YEARS AT DIAGNOSIS: 82%  
65-70 YEARS AT DIAGNOSIS: 60%

1. Possible precursor disease for MM  
2. PCL = Plasma cell leukemia  
3. Ethics approval and local governance authorisation obtained  
4. Patients at least 1 year post-diagnosis with some post-registration follow-up.

## MRDR RESEARCH HIGHLIGHTS FOR 2021

### **EpiMAP Myeloma: Epidemiological modelling to deliver better care for Australian patients with myeloma**

#### **Project Funding:**

Medical Research Future Fund (MRFF) – Targeted Health System and Community Organisation Research

---

#### **Chief investigators:**

Zoe McQuilten, Dennis Petrie, Andrew Spencer, Erica Wood, Anthony Harris, Laura Fanning

---

The project is developing and validating a novel patient-level simulation model to estimate the numbers of patients in Australia with MM who will require treatment over the next five years, their disease trajectories, outcomes, and associated quality of life and healthcare costs. The model uses real world data from the MRDR, which will be linked to Commonwealth administrative data and validated with international evidence. The model will be available to inform health-care policy and service delivery planning, including decision-making for future funding of high-cost MM therapies.



### **IMPROVE: Immunoglobulins in myeloma patients: research into outcomes, variation in practice and epidemiology**

#### **Project Funding:**

National Blood Authority Research and Development pilot project (IgP04)

---

#### **Chief investigators:**

Erica Wood, Krystal Bergin, Philip Crispin, Claire Dendle, Zoe McQuilten, Elizabeth Moore, Orla Morrissey, Arul Earnest, Andrew Spencer, Robert Weinkove.

---

Immunoglobulin (Ig) therapy is made from donated plasma. MM is one of the most common indications for its use in Australia, with increasing demand and much variation in practice. It is also costly (over \$60 million dollars spent annually in MM in Australia). The IMPROVE study has collected real world data in Australia and New Zealand on immunoglobulin use in MM in response to infection. Recruitment is complete and analysis being finalised. The study will shed light on current practice, costs and outcomes in Ig use and guide policy and clinical practice to improve the stewardship of this resource in Australia.



## **MY-PROMPT-2: More efficient delivery of high-cost standard-of-care therapies in relapsed multiple myeloma using real-time feedback of patient-reported outcome measures**

### **Project Funding:**

MRFF – Rare Cancers, Rare Diseases and Unmet Needs

---

### **Chief investigators:**

Andrew Spencer, Claudia Rutherford, John Reynolds, P Joy Ho, Zoe McQuilten, Elizabeth Moore, Tracy King, Erica Wood, Simon Harrison, Adam Irving.

---

The MY-PROMPT-2 trial will test whether real-time symptom feedback to clinicians improves duration on therapy in patients with relapsed MM receiving standard care. MM treatment is complex and costly, however survival benefits seen in clinical trials are often not reflected in clinical practice, partly because many patients stop therapy early due to side-effects, reducing the survival benefit of optimal therapy duration. If clinicians are aware of emerging symptoms, leading to timely intervention, duration on therapy could be optimised, resulting in more efficient use of these high-cost therapies, and better patient outcomes.



## **FRAIL-M: Frailty-stratified randomised controlled bayesian adaptive trial of bortezomib versus lenalidomide in transplant-ineligible myeloma**

### **Project Funding:**

MRFF – Low Survival Cancers and Diseases

---

### **Chief investigators:**

Andrew Spencer, Zoe McQuilten, Hang Quach, Peter Mollee, Erica Wood, John Reynolds, Ruth Hubbard, Richard De Abreu Lourenco.

---

The FRAIL-M trial will identify which competing treatment options are more appropriate in transplant-ineligible myeloma patients according to frailty status. Adapting certain standard treatment regimens according to frailty assessment in this patient group is recommended in Australian guidelines, however it had not been tested in a clinical trial, nor had the two most common treatment options been compared. Findings from this study will address these gaps, and provide a robust framework for optimisation of treatment in transplant-ineligible myeloma patients.



The MRDR encourages and supports all researchers in developing and pursuing their question of interest.

## MRDR COLLABORATIONS

### Asia-Pacific (APAC) MRDR

The APAC MRDR is a sister registry to the MRDR in the Asia-Pacific region, and collects the same data to facilitate comparisons between countries. APAC MRDR currently has 19 hospitals in Korea, Malaysia, Singapore, and Taiwan enrolling participants, with close to 1000 patients already and China is soon to join. There is great interest in this region and, in 2020, funders Janssen-Cilag Pty Ltd, approved a further \$5.3 million to support the continuation and expansion of the APAC MRDR. As the data mature, there is great potential for future collaborations with the ANZ MRDR and other research groups.

<https://apacmrdr.org/>



### Myeloma Australia

Myeloma Australia (MA) is the only myeloma-specific patient advocacy group in Australia. They support, educate, inform, and empower people who are living with MM, and their loved ones. The MRDR and MA work closely together, including through representation on the MRDR Steering Committee, holding the annual MRDR investigator meeting within the National Myeloma Workshop hosted by MA, funding support, and collaboration on grant applications and a range of research projects. The MRDR provides quarterly data reports to MA's Medical and Scientific Advisory Group - the peak body convened to collaborate and facilitate advances and medical care for MM in Australia.

<https://myeloma.org.au/>



### AMaRC: the Australasian Myeloma Research Consortium

AMaRC is a not-for-profit myeloma clinical trial research group composed of clinicians and scientists who develop and conduct investigator-led early phase and proof-of-concept studies, trialing novel drug and biologic products in Australia and New Zealand. AMaRC have valued partnerships with the pharmaceutical industry, the Myeloma Research Group laboratory, the Australasian Leukaemia & Lymphoma Group (ALLG), and Myeloma Australia. In some studies, AMaRC leverages the MRDR's established infrastructure and national site network as a platform for MM trials.

<https://www.amarconline.org/>





## MRDR PEER-REVIEWED PUBLICATIONS TO DATE

### Māori and Pacific peoples with multiple myeloma in New Zealand are younger and have inferior survival compared to other ethnicities: a study from the Australian and New Zealand Myeloma and Related Diseases Registry (MRDR)

Elizabeth Moore, Hilary Blacklock, Cameron Wellard, Ruth Spearing, Luke Merriman, Sarah Poplar, Anup George, Bart Baker, Henry Chan, Zoe McQuilten, Erica Wood, Andrew Spencer on behalf of the MRDR investigators. Clin Lymphoma Myeloma Leuk. Epub 8 Apr 2022, in press. doi.org/10.1016/j.clml.2022.04.004

### Receiving four or fewer cycles of therapy predicts poor survival in newly diagnosed transplant-ineligible patients with myeloma who are treated with bortezomib-based induction.

Stephen Boyle, Cameron Wellard, Elizabeth Moore, Hilary Blacklock, Simon Harrison, P Joy Ho, Jay Hocking, Zoe McQuilten, Hang Quach, Ruth Spearing, Erica Wood, Andrew Spencer, Peter Mollee, Myeloma and Related Diseases Registry investigators. Eur J Haematol. 2021 Oct;107(4):497-499. doi: 10.1111/ejh.13677u

### Real-world utilisation of ASCT in multiple myeloma (MM): a report from the Australian and New Zealand myeloma and related diseases registry (MRDR).

Krystal Bergin, Cameron Wellard, Bradley Augustson, Rachel Cooke, Hilary Blacklock, Simon Harrison, P Joy Ho, Tracy King, Hang Quach, Peter Mollee, Patricia Walker, Elizabeth Moore, Zoe McQuilten, Erica Wood, Andrew Spencer, Australian and New Zealand Myeloma and Related Diseases Registry investigators. Bone Marrow Transplant. 2021 Oct;56(10):2533-2543. doi: 10.1038/s41409-021-01308-8

### The myeloma landscape in Australia and New Zealand: the first eight years of the Myeloma and Related Diseases Registry (MRDR).

Krystal Bergin, Cameron Wellard, Elizabeth Moore, Zoe McQuilten, Bradley Augustson, Hilary Blacklock, Simon Harrison, P Joy Ho, Tracy King, Hang Quach, Peter Mollee, Patricia Walker, Erica Wood, Andrew Spencer, Australian and New Zealand Myeloma and Related Diseases Registry investigators. Clin Lymphoma Myeloma Leuk. 2021 Jun;21(6):e510-e520. doi: 10.1016/j.clml.2021.01.01

### Patient-reported outcome measures in multiple myeloma: Real-time reporting to improve care (My-PROMPT) - a pilot randomized controlled trial.

Elizabeth Moore, Tracy King, Erica Wood, Rasa Ruseckaite, Daniela Klarica, Andrew Spencer, P Joy Ho, Hang Quach, Miles Prince, Zoe McQuilten. Am J Hematol. 2020 Jul;95(7):E178-E181. doi: 10.1002/ajh.25815.

### Renal impairment at diagnosis in myeloma: patient characteristics, treatment, and impact on outcomes. Results from the Australia and New Zealand Myeloma and Related Diseases Registry.

P Joy Ho, Elizabeth Moore, Zoe McQuilten, Cameron Wellard, Krystal Bergin, Bradley Augustson, Hilary Blacklock, Simon Harrison, Noemi Horvath, Tracy King, Peter Mollee, Hang Quach, Christopher Reid, Brian Rosengarten, Patricia Walker, Erica Wood, Andrew Spencer. Clin Lymphoma Myeloma Leuk. 2019 Aug;19(8):e415-e424. doi: 10.1016/j.clml.2019.05.010.

### Myeloma in the Real World: what is really happening?

Krystal Bergin, Zoe McQuilten, Elizabeth Moore, Erica Wood, Andrew Spencer. Clin Lymphoma Myeloma Leuk. 2017 Mar;17(3):133-144.e1. doi: 10.1016/j.clml.2016.12.002.

### Design and development of the Australian and New Zealand (ANZ) myeloma and related diseases registry.

Krystal Bergin, Elizabeth Moore, Zoe McQuilten, Erica Wood, Bradley Augustson, Hilary Blacklock, P Joy Ho, Noemi Horvath, Tracy King, John McNeil, Peter Mollee, Hang Quach, Christopher Reid, Brian Rosengarten, Patricia Walker, Andrew Spencer. BMC Med Res Methodol. 2016 Nov 9;16(1):151. doi: 10.1186/s12874-016-0250-z.

# MRDR PRESENTATIONS 2021

## International Society for Quality of Life Research (ISOQOL) 28th Annual Conference, Oct 2021 (virtual)

EQ-5D-5L utility scores at diagnosis and association with improved overall survival in Australian patients with multiple myeloma: Results from the Australian & New Zealand (ANZ) Myeloma and Related Diseases Registry (MRDR) (Oral presentation). Elizabeth Moore, Cameron Wellard, Adam Irving, Erica Wood, Zoe McQuilten, Andrew Spencer.

---

## MRDR Annual Investigator and Interest Group Meeting, Sep 2021 (live webinar)

Real world myeloma in ANZ: registry progress and results. Andrew Spencer et al.

Impact of biomarker (SLiM) inclusion to MM diagnostic criteria: diagnosis with SLiM alone versus end organ damage (CRAB) in the ANZ MRDR. P Joy Ho et al.

Variation in use of Immunoglobulin in patients with myeloma. Khai Li Chai et al.

C-terminal telopeptide 1 (CTX-1) as a marker of high risk for progressing from smouldering to active myeloma. Kate Vandyke et al.

Asia-Pacific MRDR: progress and results. Naomi Aoki et al.

---

## Blood, Sep 2021 (virtual conference)

The impact of SLiM criteria in myeloma in a real-life population: patient & disease characteristics, treatment and outcome from the ANZ MRDR (Oral presentation) P Joy Ho, Elizabeth Moore, Cameron Wellard, Hang Quach, Hilary Blacklock, Simon Harrison, Emma-Jane McDonald, Zoe McQuilten, Erica Wood, Peter Mollee, Andrew Spencer.

Tandem autologous-allogeneic-SCT in relapsed multiple myeloma: a joint report from the Alfred and Myeloma and Related Diseases Registry (MRDR) (Poster) Aditya Tedjaseputra, Cameron Wellard, Tongted Das, Andrew Spencer.

Causes of death in multiple myeloma in Australia: results from the Australian and New Zealand Myeloma and Related Diseases Registry (Narrated poster) Rosalyn Cao, Elizabeth Moore, Cameron Wellard, Bradley Augustson, Philip Campbell, Simon Harrison, P Joy Ho, Jay Hocking, Tracy King, Zoe K McQuilten, Peter Mollee, H. Miles Prince, Hang Quach, Erica Wood, Andrew Spencer.

Higher EQ-5D-5L utility scores at diagnosis are associated with improved overall survival in Australian patients with multiple myeloma: Results from the Australian & New Zealand (ANZ) Myeloma and Related Diseases Registry (MRDR) (Narrated poster) Elizabeth Moore, Cameron Wellard, Adam Irving, Erica Wood, Zoe McQuilten, Andrew Spencer.

---

## International Myeloma Workshop, Sep 2021 (hybrid conference, Vienna-based)

The impact of SLiM criteria in myeloma in a real-life population: clinical characteristics, treatment and outcome from the Australian and New Zealand Myeloma and Related Diseases Registry (MRDR) (Narrated poster) P Joy Ho, Elizabeth Moore, Cameron Wellard, Hang Quach, Hilary Blacklock, Simon Harrison, Emma-Jane McDonald, Zoe McQuilten, Erica Wood, Peter Mollee, Andrew Spencer.

Tandem autologous + non-myeloablative allogeneic stem cell transplantation in relapsed multiple myeloma: an Australian joint report from the Alfred and Myeloma and Related Diseases Registry (MRDR) (Poster) Adi Tedjaseputra, Cameron Wellard, Tongted Das & Andrew Spencer.

---

## Nursing Symposium, International Myeloma Workshop, Sep 2021

Higher EQ-5D-5L utility scores at diagnosis are associated with improved overall survival in Australian patients with multiple myeloma: Results from the Australian & New Zealand (ANZ) Myeloma and Related Diseases Registry (MRDR) (Oral presentation) Elizabeth Moore, Cameron Wellard, Adam Irving, Erica Wood, Zoe McQuilten, Andrew Spencer.

---

## Using PROMs 'Down-under' – Supported by ISOQOL, July 2021 (virtual Sydney-based conference)

Patient-reported outcome measures in multiple myeloma: real-time reporting to improve care (My-PROMPT) - a pilot randomised controlled trial (Oral presentation) Elizabeth Moore, Tracy King, Erica Wood, Daniela Klarica, Rasa Ruseckaite, Andrew Spencer, P Joy Ho, Miles Prince, Hang Quach, Alicia Snowden, Zoe McQuilten.

---

## MRDR SITES AND PRINCIPAL INVESTIGATORS

Adelaide Cancer Centre: Stanley Cheung

Alfred Hospital: Andrew Spencer

Austin Hospital: Andrew Lim

Bairnsdale Regional Health Service: Amanda Ormerod

Ballarat Hospital: Swe Htet

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 Coast Haematology: Cecily Forsyth

Central Gippsland Health Service: Amanda Ormerod

Christchurch Hospital: Emma-Jane McDonald

Concord Hospital: Jane Estell

Dunedin Hospital: Ian Morison

Epworth Freemasons Hospital: Miles Prince

Flinders Medical Centre: Craig Wallington-Gates

Frankston Hospital: Patricia Walker

Geelong Hospital: Philip Campbell

Griffith Hospital: Nada Hamad

Hollywood Private Hospital: Bradley Augustson

ICON Cancer Care: Ian Irving

Latrobe Regional Hospital: Tricia Wright

Launceston General Hospital: Jessica Heenan

Lismore Hospital: Louise Imlay

Liverpool Hospital: Sylvia Ling

Lyell McEwin Hospital: Stanley Cheung

Middlemore Hospital: Rajeev Rajagopal

Monash Medical Centre: Michael Low

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

Peter Mac / Royal Melbourne: Simon Harrison

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: Andrew Birchley

Wagga Wagga Hospital: Nada Hamad

Wellington Hospital: Anup George

Whangarei Hospital: Sarah Poplar

The MRDR thanks participating individuals and sites,  
and our steering committee for all their work and contribution.

### MRDR Steering Committee

**Prof Andrew Spencer:**

Alfred Hospital /  
Monash University VIC

**Dr Bradley Augustson:**

Sir Charles Gairdner Hospital WA

**Dr Krystal Bergin:**

Alfred Hospital VIC

**Prof Simon Harrison:**

Peter Mac/Royal Melbourne VIC

**Prof Joy Ho:**

Royal Prince Alfred Hospital NSW

**Dr Tracy King:**

Royal Prince Alfred Hospital NSW

**A/Prof Zoe McQuilten:**

Monash University VIC

**A/Prof Peter Mollee:**

Princess Alexandra Hospital QLD

**Prof Hang Quach:**

St Vincent's Hospital,  
Melbourne VIC

**Dr Rajeev Rajagopal:**

Middlemore Hospital NZ

**Mr Brian Rosengarten:**

Myeloma Australia

**A/Prof Craig Wallington-Gates:**

Flinders Medical Centre SA

**Prof Erica Wood:**

Monash University VIC

### MRDR Management Committee

Coordinating Principal Investigator:

**Prof Andrew Spencer**

Head of Transfusion Research Unit:

**Prof Erica Wood**

Associate Investigator:

**A/Prof Zoe McQuilten**

Research Fellow/ANZ MRDR

Project Manager:

**Dr Elizabeth Moore**

Data Manager:

**Dr Cameron Wellard**

Research Officer:

**Dr Laura Sellick**

Data Officer:

**Dr Fiona Chen**

Senior Projects Officer:

**Mr Neil Waters**

APAC MRDR Project Manager:

**Ms Naomi Aoki**

Business Development Project

Manager (AMaRC):

**Mr Khoa Le**

Thank you to the following MRDR industry funding partners. We  
appreciate your support and look forward to a very productive 2022.

Abbvie, Amgen, Antengene, Bristol-Myers Squibb, Celgene, Gilead,  
GlaxoSmithKline, Janssen-Cilag, Novartis, Sanofi, Takeda

### TO CONTACT THE MRDR:

E: [sphpm-myeloma@monash.edu](mailto:sphpm-myeloma@monash.edu)

T: 1800 811326

W: [mrd.net.au](http://mrd.net.au)