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How to contact us

Are you or your hospital interested in participating in the MRDR or would you like to find out more information?

Feel free to contact us on:

Phone: 1800 811 326 (AU)
0800 666 274 (NZ)

Email: torc.sphpm@monash.edu

WELCOME

Welcome to the Myeloma and Related Diseases Registry (MRDR) inaugural newsletter! We hope that you enjoy this bi-annual newsletter which will update you on all our latest news, progress and events. Happy reading!

OVERVIEW OF THE REGISTRY

The Australian and New Zealand Myeloma and Related Diseases Registry is a register of patients (≥ 18 years) diagnosed with myeloma or a related disease. The registry provides a means of collecting data on patterns of treatment and variation in patient outcomes (both survival and quality of life). It will also enable clinicians to benchmark against national and international standards and allow evaluation of the translation of advances in therapy (such as introduction in new targeted therapies) into long-term outcomes outside the setting of clinical trials.

Data on eligible patients is entered into a purpose-built, web-based database by clinicians (or staff under their direction) at participating sites. Data management and analysis is undertaken by the Department of Epidemiology and Preventive Medicine (DEPM) at Monash University and interpreted with input from clinicians specialising in myeloma.

PROGRESS TO DATE

The past year has been a busy one for the Registry! In early 2012, the MRDR Steering Committee was formed and, shortly after, the MRDR data elements and definitions were finalised. By December 2012, we had constructed the MRDR web database and it went “live” for data collection in January 2013. Data on diagnosis, co-morbidities, therapy (including supportive care) and outcomes (including quality of life) is collected for all new cases registered on the database.

Currently, we have 10 hospitals from across Australia and New Zealand participating in the study (Fig 1). The registry intends to expand and include most Australian and New Zealand sites treating myeloma and its related diseases.

As of the 10th of September 2013, a total of 99 participants from 5 of the participating sites have

been registered so far (Fig 2). The team would like to thank all the hard working and *patient* data managers and local investigators for getting us this far!

So what’s next for the Registry? Well, in the near future, we will also be:

- Developing hospital reports (providing de-identified risk-adjusted outcome data to allow individual sites to benchmark performance with comparable health services)
- Upgrading the MRDR Database
- Developing a biobank (please see Page 3 for more details)
- Constructing a MRDR website
- Performing the first audit on the database
- Linking with State cancer councils to check case ascertainment



Fig. 1. MRDR Sites with ethical approval

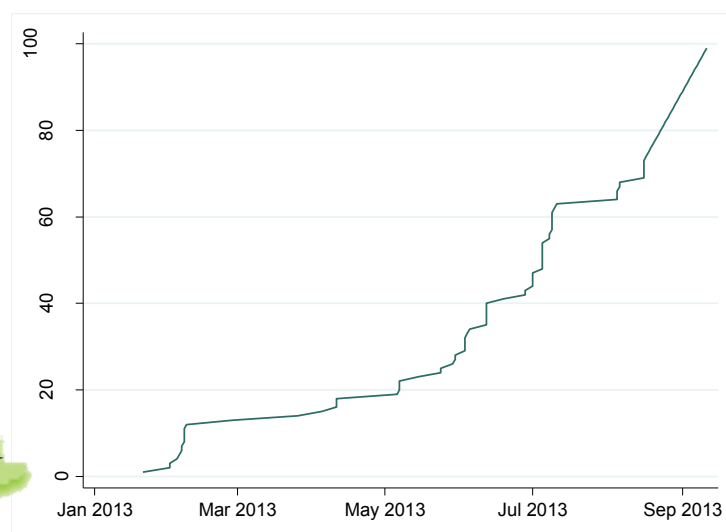


Fig. 2. Cases accrued since January 2013 Page 2

MYELOMA 1000 PROJECT

The Myeloma 1000 Project aims to establish a repository of blood specimens that will be available for the future assessment of biomarkers (proteins and/or genes) that better predict patients at risk of developing myeloma or a related disease, accelerated disease progression and their response to treatment.

The project will leverage off the MRDR by linking biological information with clinical data collected by the Registry. Blood samples will be taken from eligible participants and stored or 'banked' at Alfred Hospital in Melbourne, Victoria.

Through linking prospective, long-term clinical data with biological information on a large cohort of newly diagnosed myeloma patients, the



Myeloma 1000 Project will enable correlative studies that will be highly valuable in informing optimal treatment strategies for myeloma and its related diseases.

Bristol-Myers Squibb and Amgen Australia have kindly provided initial funding for the project. Sample collection is due to begin in early 2014.

MRDR INTEREST GROUP MEETING 2013

We are hosting our inaugural Interest Group Meeting during the HAA 2013 Annual Scientific Meeting from 7.00am to 8.15am on the 21st October 2013.

The meeting is open to anyone who is interested, involved or would like to be involved in the project. We will be presenting on both the Registry and the Biobank and a light breakfast will be provided.



If you are attending HAA this year and would like to hear more about the Registry, please feel free to come along.

Contact Naomi (torc.sphpm@monash.edu) for more information or to reserve a spot.

PROJECT TEAM

Lead Investigator



Prof Andrew Spencer

Project Manager



A/Prof Erica Wood

Research Fellow



Dr Zoe McQuilten

Project Officer



Ms Naomi Aoki

UPDATE TO DATA MANAGERS AND LOCAL INVESTIGATORS

Database Update: The MRDR Database will be updated over the next couple of months. The updates will fix reported bugs, improve user experience and remove/edit current data items. A list of changes will be circulated for comment shortly. If you have any feedback or suggestions, please do not hesitate to email Naomi Aoki (torc.sphpm@monash.edu).

Project documentation: With the updates to the database, new versions of the database user manual will be distributed.

Data Managers' Meeting: Regular Data Managers' Meetings via teleconference will be scheduled. It will be a chance for interested data managers to share knowledge, provide feedback to the project team and get updates. Naomi will be in contact to find an ideal date.

Lastly, a big THANK YOU! The MRDR Project Team are sincerely grateful for all of the excellent work that you have put into the registry this past year!

MRDR STEERING COMMITTEE

Professor Andrew Spencer (Chair), *Alfred Health/ Monash University*

Dr Bradley Augustson, *Sir Charles Gairdner Hospital*

Dr Hilary Blacklock, *Middlemore Hospital*

Professor Joy Ho, *Royal Prince Alfred Hospital*

Dr Noemi Horvath, *Royal Adelaide Hospital*

Ms Tracy King, *Royal Prince Alfred Hospital*

Dr Louise Phillips, *Calembeena Consulting*

Dr Zoe McQuilten, *Monash University*

Professor John McNeil, *Monash University*

Dr Peter Mollee, *Princess Alexandra Hospital*

Professor Chris Reid, *Monash University*

Mr Brian Rosengarten, *Myeloma Foundation of Australia*

Dr Patricia Walker, *Peninsula Health / Alfred Health*

A/Professor Erica Wood, *Monash University*