



Introduction to the Lymphoma and Related Diseases Registry



MONASH
University

Medicine, Nursing and Health Sciences

OVERVIEW AND AIMS

The Lymphoma and Related Diseases Registry (LaRDR) was established in 2016 and is administered by Monash University in Melbourne. LaRDR a registry of patients (≥ 18 years) diagnosed with all forms of lymphoma and related disease such as B and T/ NK cell non-Hodgkin Lymphoma and Hodgkin Lymphoma

The aim of the LaRDR is to monitor access to care, benchmark outcomes nationally and internationally, monitor trends in incidence and survival, explore factors that influence outcomes including survival and quality of life and act as a resource for clinical trials. It will also enable clinicians to benchmark against national and international standards and allow evaluation of the translation of therapy such as the introduction of new target therapies.

RECRUITMENT

In the short time that LaRDR has been active a milestone was reached in May with the 100th patient registered. The research team thanks all of the patients, data managers and clinicians for their support. Five sites now contribute to the data registry.



ACTIVE SITES

- QLD
 - Princess Alexandra Hospital
- NSW
 - Concord Hospital
- VIC
 - Monash Medical Centre
 - Austin Hospital
- WA
 - Fiona Stanley Hospital

HOW PATIENTS CAN BE INVOLVED

Patients (≥ 18 years and recently diagnosed with lymphoma) are invited to join the registry by clinical staff at participating hospitals. Inclusion on the LaRDR does not involve any procedure or change in treatment and participants can opt-off the registry at any time.

If you would like to know more about the LaRDR:

Visit our website: www.lardr.org

Call: 1800 811 326

Email: SPHPM-Lymphoma@monash.edu



MEET OUR DATA CONTRIBUTORS

Tania Cushion is a Lymphoma Clinical Nurse Consultant who works on the LaRDR registry at Austin Hospital.

What does your role involve on a day-to-day basis?

The most important part of my role is to act as a primary point of contact for patients. This involves seeing patients either in clinics, day oncology or when they are inpatients.

For someone who has just received a diagnosis of cancer, taking the next steps can be confusing and overwhelming and this can be a barrier to accessing care. I ensure that patients understand their diagnosis and treatment plan, and co-ordinate their care. This can range from chemotherapy education, psychological support, fertility counselling and referrals to community care and various allied health services.

Throughout a patient's treatment plan I am available to provide reassurance, support, or to organise review as needed. In addition to this, I provide support and education for nursing staff.

And, you find time to enter patients into the registry. What do you see as the benefits of tracking lymphoma cases?

I've been involved in data collection for many years in past roles, and as such I can see the benefits in patient outcomes that this can bring.

Having a nationwide database of lymphoma will allow us to identify what treatments are working and to learn from each other to provide the best possible therapy for patients.

Keeping track of what we're doing now will allow future clinicians and researchers to follow the trajectory of the registry, hopefully resulting in a greater understand of lymphoma and how to treat it.

SPONSORS

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