

LaRDR Sites and Principal Investigators

(italics = governance approval pending)

Alfred Hospital: Susan Morgan
Austin Hospital: Eliza Hawkes
Ballarat Hospital: Geoffrey Chong
Barwon Health: Sumita Ratnasingam
Box Hill Hospital: Denise Lee
Canberra Hospital: Dipti Talaulikar
Concord Hospital: Judith Trotman
Epworth Hospital: H. Miles Prince
Fiona Stanley Hospital: Dustin Hall
Gold Coast University Hospital: Tara Cochrane
Gosford Hospital: Tasman Armytage
Liverpool Hospital: *Nicolas Viiala*
Monash Health: Stephen Opat
Peter MacCallum Cancer Centre: Michael Dickinson
Port Macquarie Base Hospital: *Jack Simpson*
Princess Alexandra Hospital: Colm Keane
Royal Adelaide Hospital: Pratyush Giri
Royal Darwin Hospital: *Emma Palfreyman*
Royal Hobart Hospital: Anna Johnston
Royal North Shore Hospital: *Luke Coyle*
Sir Charles Gairdner Hospital: Chan Cheah
St Vincent's Hospital, Melbourne: Matthew Ku
St Vincent's Hospital, Sydney: Nada Hamad
Sunshine Coast University Hospital: Manjunath Narayana
Sunshine Hospital: Duncan Carradice
Toowoomba Hospital: Howard Mutsando
Townsville Hospital: Joel Wright

LaRDR Steering Committee

Stephen Opat (chair): Monash Health
Leanne Berkahn: Auckland Hospital, NZ
Chan Cheah: Sir Charles Gairdner Hospital
Michael Dickinson: Peter MacCallum Cancer Centre
Maher Gandhi: Princess Alexandra Hospital
Pratyush Giri: Royal Adelaide Hospital
Eliza Hawkes: Austin Hospital
Anna Johnston: Royal Hobart Hospital
Colm Keane: Princess Alexandra Hospital
Zoe McQuilten: Monash University
Stephen Mulligan: Royal North Shore Hospital
Dipti Talaulikar: Canberra Hospital
Judith Trotman: Concord Hospital
Erica Wood: Monash University

Working groups

Chronic Lymphocytic Leukaemia

Stephen Mulligan (chair): Royal North Shore Hospital
Xavier Badoux: St George Hospital
Gavin Cull: Sir Charles Gairdner Hospital
Constantine Tam: Peter MacCallum Cancer Centre
Bryone Kuss: Flinders Medical Centre
Paula Mariton: Princess Alexandra Hospital
Manjunath Narayana: Sunshine Coast University Hospital
Stephen Opat: Monash Health
Sumita Ratnasingam: Geelong Hospital
Dipti Talaulikar: Canberra Hospital
Erica Wood: Monash University

Pathology Review/WHO Classification

Dipti Talaulikar (chair): Canberra Hospital
Simone Birch: Princess Alexandra Hospital
Christina Brown: Royal Prince Alfred Hospital
David Ellis: Clinpath Pathology
Yasmin Harvey: Sullivan Nicolaides Pathology
Sam Hitchens: University of Tasmania
Sanjiv Jain: Canberra Hospital
Peter Jessup: Royal Hobart Hospital
Surender Juneja: Peter MacCallum Cancer Centre
Daniel Kearney: Royal Adelaide Hospital
Beena Kumar: Monash Health
Stephen Lade: Peter MacCallum Cancer Centre
Kenneth Lee: University of Sydney
Connall Leslie: University of Western Australia
Eileen Long: Hobart Pathology
Adrienne Morey: Canberra Hospital
Lakshmi Nath: Clinpath Pathology
Debbie Norris: QML Pathology
Andrew Parker: St Vincent's Hospital, Sydney
Jeremy Parry: Fiona Stanley Hospital

LaRDR Administration

Administration: School of Public Health and Preventive Medicine, Monash University
Coordinating Principal Investigator: Stephen Opat
Investigators: Erica Wood, Zoe McQuilten
Senior Research Officer: Gayathri St George
Data Manager: Cameron Wellard
Research Officer: Michelle Zheng (to May 2020), Eliza Chung
Senior Projects Manager: Neil Waters

Welcome to the LaRDR report for 2020! Now into our fifth year of data collection, we send a big “thank-you” to all registry participants and supporters for your great efforts to make the registry such a success.

MESSAGE FROM THE CHAIR

I am delighted to share this report on LaRDR's progress in 2020. The registry continues to grow, with 27 sites participating and more joining, and 4226 patients registered to date. We are undertaking important research using LaRDR data, as outlined below, and look forward to your ongoing input to the research program.

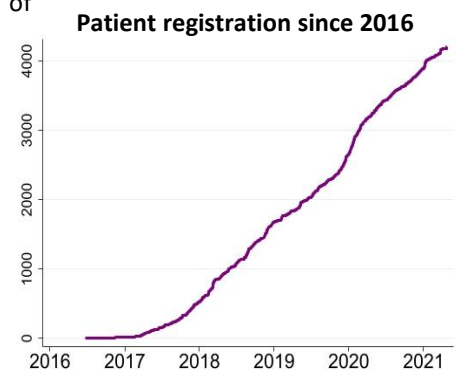
We have received positive feedback on the site reports. We hope you find these useful for your own practice and to share with your colleagues for quality review purposes. We have made a number of further improvements to the user experience for data entry this year, based on your suggestions through the data validation working group. These will enable LaRDR to continue to improve our data quality and provide our results to inform practice in a rapidly changing therapeutic landscape.

I thank the **LaRDR team at Monash University** who keep the engine running on our behalf, all the site **Principal Investigators and staff** who invite patients to participate and enter data into the registry, and our **industry and community partners** who support us. We literally could not do it without all of you!

LaRDR ACTIVITIES AND PROGRESS

Governance and management: The registry is overseen by the national **LaRDR Steering Committee** and managed by Ms Gayathri (Gaya) St George and the LaRDR team at Monash University's School of Public Health and Preventive Medicine. LaRDR uses an “opt-off” consent model to enable maximum participation.

Participation: 23 sites have already contributed data to LaRDR, with recruitment reaching over 4200 in April 2021. The median age of enrolled patients is 65 years, and 60% are male. Major diagnoses of participants include mature B-cell non-Hodgkin lymphoma (70.5%), Hodgkin lymphoma (14%), mature T-cell and NK-cell NHL (5%), CLL (10%) and post-transplant lymphoproliferative disorder (0.5%). CLL case numbers are increasing since the addition of a CLL-specific case report form, designed with input from the **CLL Working Group**.




The **LaRDR Pathology Review committee** chaired by A/Prof Dipti Talaulikar has been established to ensure the accurate and consistent diagnosis of cases entered into the registry, and to enable interpretation of treatment and outcomes reported by the registry. The Pathology Review Committee published a practical guide to laboratory investigations in Waldenström macroglobulinaemia (Maqbool et al, 2020). The **World Health Organization (WHO) Classification Working Group** provide support to ensure the disease classifications used in the registry are up-to-date with the WHO classifications. The **Data Validation Working Group** (Dr Allison Barraclough and Tania Cushion, Austin Health; and Dr Joshua Casan and Jing Huang, Monash Health; working with the Monash University team, continue to identify potential improvements to the LaRDR database, while ensuring that the captured data are meaningful and relevant.

LaRDR can now provide custom-built annual data reports for participating sites. These hospital-specific data analyses further support benchmarking and practice improvement. We value your ongoing feedback on the reports and how they are used in your institution.

REGISTRY PROJECTS

A few highlights from current LaRDR projects are outlined below. *LaRDR welcomes suggestions for analyses of registry data and new project ideas using the registry.* Please contact the LaRDR team and we will provide you with the data access policy and project proposal template, and assistance with analysis as needed.

ICAN: Immunoglobulin use and outcomes in Chronic lymphocytic leukaemia And Non-Hodgkin lymphoma  is a registry-based study funded by the National Blood Authority and led by A/Prof Zoe McQuilten from Monash University. ICAN has recently completed recruitment of detailed 'real world' clinical and laboratory data on infections and immunoglobulin and antibiotic use for patients with CLL and NHL. The results will help to improve infection prevention and treatment for patients, and, where possible, rationalise the use of immunoglobulin therapy. Follow-up data collection is underway, and the project team thanks all participating sites for their contributions.

A/Prof Eliza Hawkes (Austin/Eastern Health) and Prof H. Miles Prince (Epworth/Peter MacCallum Cancer Centre) led LaRDR's contribution to the international **T-cell Project 2.0** collaborative project, collecting data on patients with newly diagnosed peripheral T-cell lymphoma, with participation from Europe, United States, South America, Australia and Asia. Data analysis is complete and an abstract is being published.

Dr Stephen Walker (St Vincent's Hospital, Melbourne) together with Dr Matthew Ku and Prof Con Tam (Peter MacCallum Cancer Centre) are conducting a study titled: **Factors influencing outcome in Richter's transformation; results of a multicentre retrospective study on Richter's transformation of CLL or small lymphocytic lymphoma to diffuse large B-cell lymphoma or Hodgkin lymphoma.** They aim to identify prognostic factors in the Australasian cohort and provide insights in improving current treatment standards. LaRDR contributed retrospective information about CLL/SLL patients pre- and post-transformation.

Dr Michael Shipton is undertaking a **review of patterns of treatment and survival outcomes for patients with large B-cell lymphoma**, supervised by Dr Michael Dickinson (Peter MacCallum Cancer Centre/Royal Melbourne Hospital) and Dr Gareth Gregory (Monash Health). Dr Adrian Minson is conducting a **review of the patterns of treatment and outcomes for patients with mantle cell lymphoma**, in collaboration with the Australasian Lymphoma Alliance. LaRDR was pleased to contribute data for these analyses.

A/Prof Eliza Hawkes and Dr James Nguyen (Eastern Health) are analysing LaRDR data to describe **characteristics of Hodgkin lymphoma in Australia.** The study aims to identify the clinical, demographic and treatment patterns of Hodgkin lymphoma patients to provide evidence to fill the existing knowledge gap and allow comparison with other populations. Data analysis is in progress utilising SafeHaven, a secure platform for sensitive data sharing, supported by the Monash secure e-research platform.

LaRDR thanks participating sites for their contributions to analyses of ibrutinib and polatuzumab use in LaRDR patients also enrolled in the **Named Patient Programs** for these agents.

REGISTRY MEETINGS and PRESENTATIONS

Recruitment status and characteristics of the captured diagnoses in LaRDR were presented at the **International T-Cell Lymphoma Forum** by A/Prof Eliza Hawkes in San Diego in January 2020. We look forward to her upcoming presentation at the **13th Annual T-Cell Lymphoma Forum**. An abstract describing the T-Cell lymphoma cases in LaRDR is underway.

In lieu of the usual annual investigator breakfast, LaRDR investigators, friends and supporters gathered online in November 2020 with colleagues from the Australasian Lymphoma Alliance for the **2020 ALA/LaRDR Annual Investigator Meeting**. The **ALA**, led by Professor Chan Cheah and colleagues, aims to increase national collaborative lymphoma clinical research output and facilitate engagement with international collaborators and industry. Prof Chan Cheah (Chair, ALA) and Prof Stephen Opat (Chair, LaRDR) provided updates on recent ALA and LaRDR developments, respectively. Participants enjoyed presentations from Dr Michael Shipton (Peter MacCallum Cancer Centre), Dr Greg Hapgood (Princess Alexandra Hospital), Dr Kate Manos (Austin Health), and Dr Pietro Di Ciaccio (St Vincent's Health Network) about their research underway, followed by discussion. ALA and LaRDR look forward to continuing to work together to encourage collaboration for lymphoma research across Australia.



LaRDR looks forward to the coming **Blood 2021** meeting, including opportunities to share our data. An abstract outlining the development of LaRDR over the past five years will be submitted. LaRDR has also supported collaborators in data cleaning and analysis for their abstract submissions.

To contact LaRDR

Website: www.lardr.org

Email: sphpm-lymphoma@monash.edu

Phone: 1800 811 326

LaRDR appreciates the support from these organisations:

