



Lymphoma

— and —

Related Diseases Registry

NEWSLETTER JUNE 2017

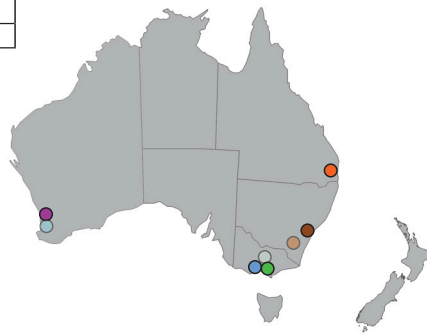
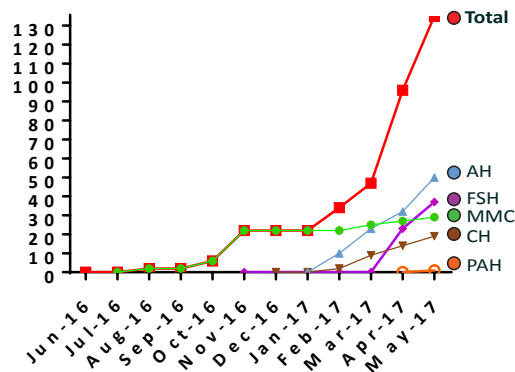


Registry News

100 cases

It is still early days but we recently celebrated the 100th case entered into the registry nationwide. Thanks to everyone involved!

Site	Status	Cases
● Monash Medical Centre, VIC	Active	28
● Austin Hospital, VIC	Active	50
● Fiona Stanley Hospital, WA	Active	37
● Concord Hospital, NSW	Active	19
● Princess Alexandra Hospital, QLD	Active	1
● Sir Charles Gairdner Hospital, WA	Pending	0
● Canberra Hospital, ACT	Pending	0
● Peter MacCallum Cancer Centre, VIC	Pending	0
● Total		135



5 sites now active and collecting data

We now have 5 sites who have already contributed data to the registry. Three sites have ethics applications underway, and we are seeking expressions of interest from new sites in Australia and New Zealand.

Increased data entry payments

To facilitate training and familiarisation with the registry, the initial data entry payment has been doubled from \$50/case to \$100/case. This increase is currently approved for the first 800 cases nationwide.

New website

Our new website is live. The aim of the website currently is to inform clinicians, stakeholders and patients on the aims and outcomes of the LaRDR registry.

This issue

- > Registry News
- > Site Reminders
- > Thank-you

Registry staff

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Steering Committee

Prof Stephen Opat (chair)

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Dr Chan Cheah
Dr Michael Dickinson
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For more information

If you are interested in the LaRDR Registry please contact us:

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Site Reminders

6, 12 & 24 month time points

Reports are located in the left hand menu of RedCap to generate lists of patients requiring follow-up at your site. This data is important to track outcomes of treatment.

Case information report
6 month review needed
12 month review needed
24 month review needed



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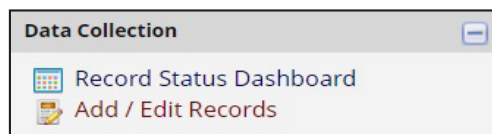
Incomplete data

When a case report form (CRF) is finished and can be included in any future analysis it is marked as complete, which displays as green in the Record Status Dashboard. There are three options (and colours) for CRF status once data entry has commenced:

Legend for status icons:

- Incomplete ● Incomplete (no data saved) ?
- Unverified
- Complete

We suggest using 'Incomplete' for a CRF that you have begun but not finished, and 'Unverified' for a CRF that is otherwise complete but awaiting clarification on a field. You can check the status of your existing forms using the Record Status Dashboard:



Patient information	Diagnosis	Medical history	Laboratory data	Staging / Pathology	Prognostic score	Viral infection diagnostics	Immunophenotype	Cytogenetics/FISH	Molecular studies	Primary treatment plan
Baseline (Diagnosis)	Baseline (Diagnosis)	Baseline (Diagnosis)	Baseline (Diagnosis)	Baseline (Diagnosis)	Baseline (Diagnosis)	Baseline (Diagnosis)	Baseline (Diagnosis)	Baseline (Diagnosis)	Baseline (Diagnosis)	Baseline (Diagnosis)
●	●	●	●	●	●	●	●	●	●	●
●	●	●	●	●	●	●	●	●	●	●
●	●	●	●	●	●	●	●	●	●	●
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Feedback

The registry continues to evolve as more cases are entered with varying disease subtypes. We encourage feedback on the registry, especially data input issues.

Thank-you

A huge thanks to everyone who has contributed their time and expertise to the registry so far. We look forward to continuing the upward trajectory in the year to come and starting to analyse the data.