

ACQUIRE Study Update, March 2019



Welcome to the March 2019 edition of the aCQuiRE Study newsletter!

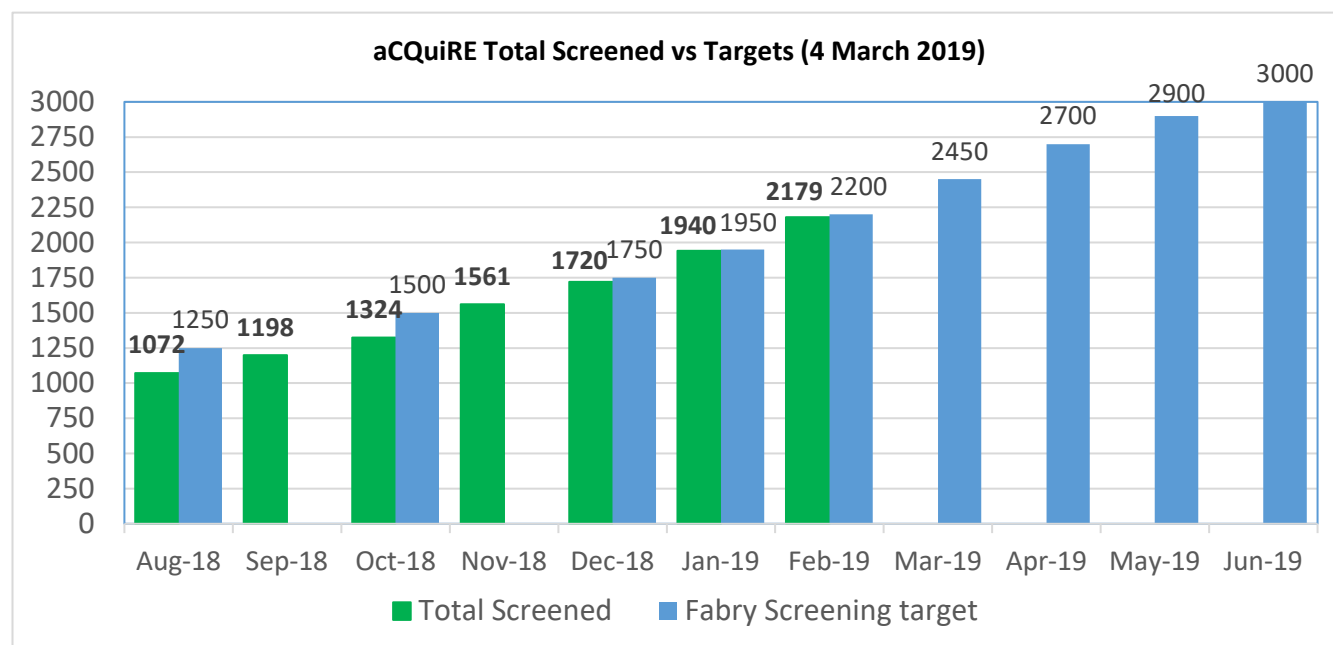
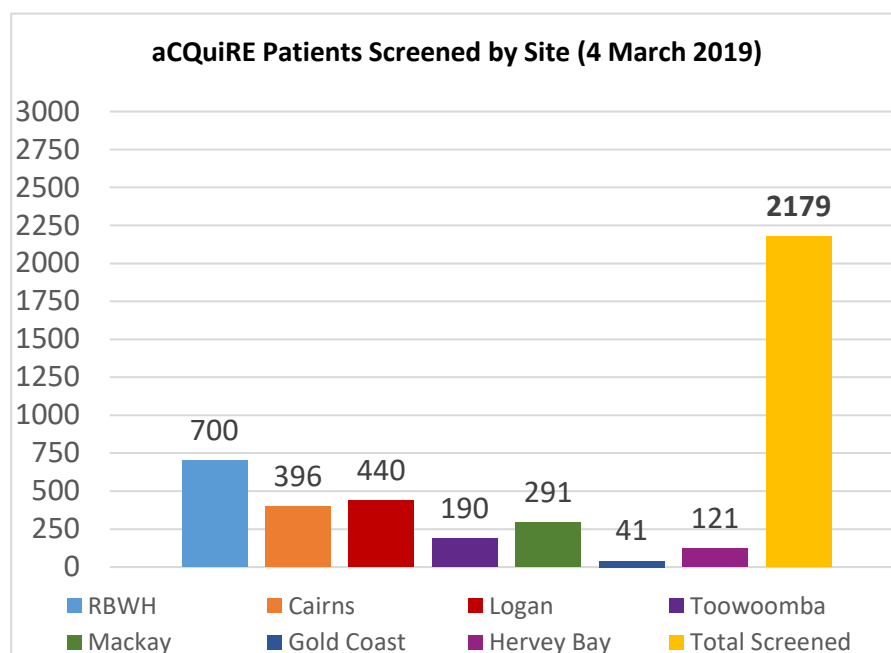
2,179 patients have now been screened for Fabry disease as part of the aCQuiRE Study!

The Kidney Health Service at RBWH and Renal Services at Mackay Base Hospital have been our biggest screeners recently, screening 80 and 64 patients last month respectively.

We have four months left to screen just over 800 patients. This means we need to screen at least 200 patients across Queensland each month for the next four months.

I know that there are still lots of potential participants at our sites and there remains more than

\$120,000 of funding allocated for reimbursement of nursing time at \$150 per patient. This funding is available on a competitive recruitment basis until 30 June 2019 until 3,000 patients have been screened. Apart from the satisfaction of reaching a screening target of 3,000, I would love to see this money go to sites, which could be used to further research and professional development.



For further information about the aCQuiRE Study, please contact:

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After 30 June, there will be an additional two months for finalisation of any follow-up Fabry testing, collection of missing data, and reporting results to patients. Follow-up testing needs to be finalised by 31 August 2019.

Fabry Cases

One new case of Fabry disease has been identified in a male patient from Logan Hospital. This patient has had their diagnosis confirmed through genetic testing and has been referred to the statewide Fabry treatment service. Two patients from KHS at RBWH, have previously identified cases of Fabry disease. One of these cases has been confirmed through Lyso-GB3 testing and we are awaiting Lyso-testing of the other patient to confirm their diagnosis. Such confirmation of known cases of Fabry disease is vital for validation of aCQuiRE screening process.

Site Investigator Meeting

I will be hosting the next Site Investigator meeting around mid-March and sending out a Doodle poll shortly.

Site snapshot

It takes a lot of man power to run aCQuiRE:

- ✚ 7 sites are screening patients across Queensland, from Gold Coast in the south, to Cairns in the North and to Darling Downs in the West.
- ✚ Each site has a lead site investigator, as well as a site coordinator.
- ✚ 19 nurses have been trained and inducted to screen patients for Fabry disease across these sites.

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