

# ACQUIRE Study Update, April 2019

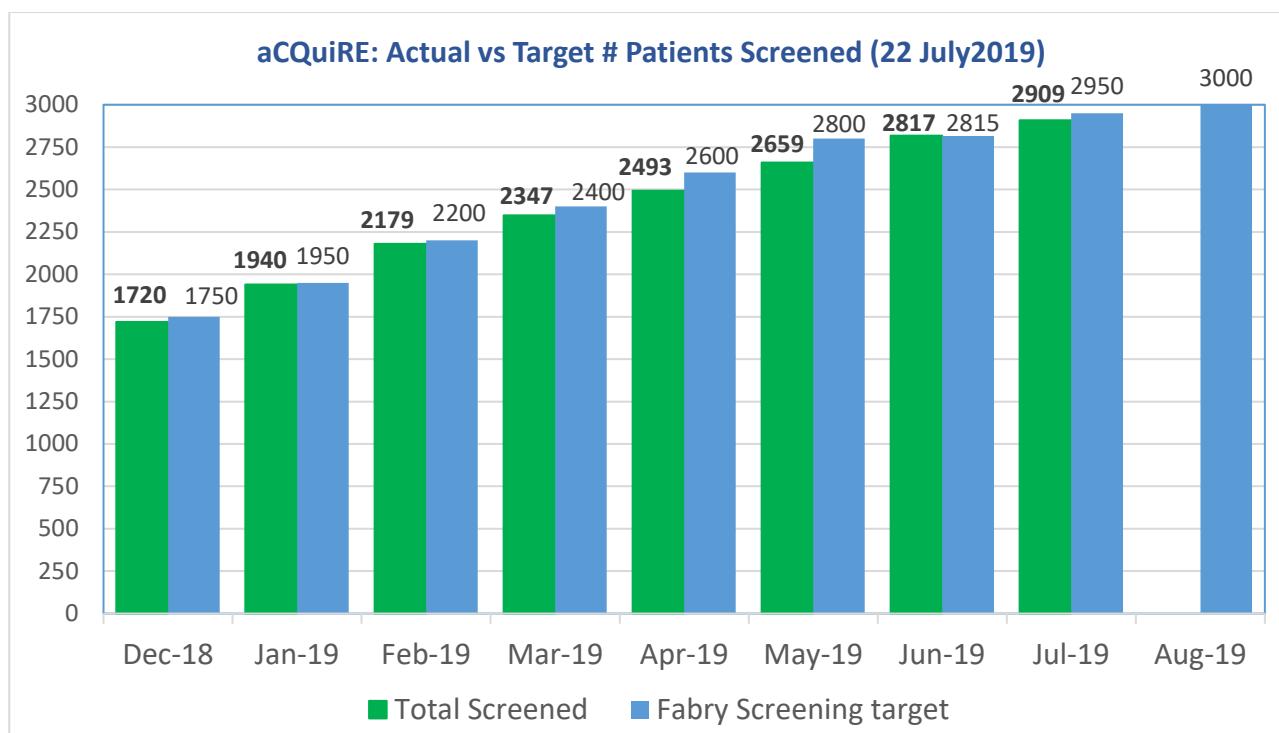
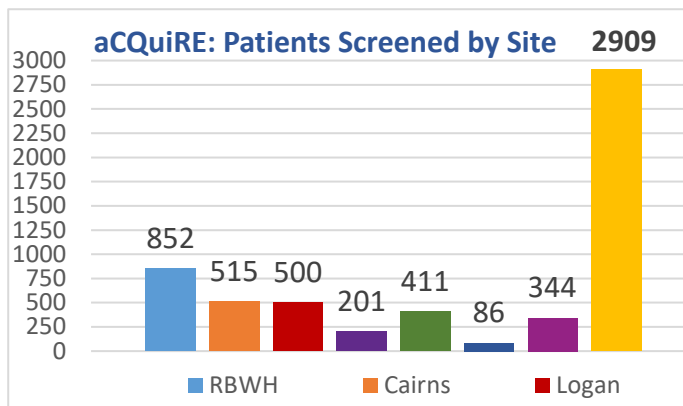


Welcome to the July 2019 edition of the aCQuiRE Study newsletter!

## 2,909 patients have been screened for Fabry disease as part of the aCQuiRE Study!

Thanks to your massive efforts, we are now screening the final 100 patients needed to achieve our target of 3,000 patients.

Screening can continue until 30 August 2019 but it would be great to finalise initial screening around the mid-August. There will be an additional two months, until 31 October 2019, for finalisation of follow-up Fabry testing, collection of missing data, and reporting of results to patients.



### Reminders

- **Don't forget to include the A4 SA Pathology Request form with each DBS card**, otherwise SA Path don't know to send a copy of the report to the site coordinator and myself. This means chasing up of reports and a time lag in finalising patients testing.
- **Each participating patient requires a letter to finalise their participation in the study.** There is a proforma available for this if needed.
- Due to extension to the screening timeline, we have less time to finalise missing data by 31 October. I will be performing data quality checks over the next several weeks and advise sites where missing data needs to be follow up. I will assist where able but **it is the responsibility of each site to follow up with missing data.**

For further information about the aCQuiRE Study, please contact:

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