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Welcome to the ACFDR Newsletter

Issue #12

August 2021



The **ACFDR Team** would like to say a huge thank you to all of you for your continuous dedication and hard work.

We recognise your extremely busy schedules, and difficulties faced with ongoing lockdowns around the country, we appreciate the time you put aside to ensure **quality data** entry into the registry.



2021 Data Entry Deadlines

2021 Data Entry Required	Deadline for payment
Q1 2021 (clinical measures, hospital/clinics/home Abx, microbiology and Quarterly Sign off)	31 st May 2021
Q2 2021 (clinical measures, hospital/clinics/home Abx, microbiology and Quarterly Sign off)	31 st August 2021
Q3 2021 (clinical measures, hospital/clinics/home Abx, microbiology and Quarterly Sign off)	30 th November 2021
1. Q4 2021 (clinical measures, hospital/clinics/home Abx, microbiology and Quarterly Sign off) 2. 2021 Annual Data, Complications and treatment.	28 th February 2022

Quarter 2, 2021 data entry will be due **31st August**.

This includes any clinical measures, hospital/clinic visits/ microbiology and completion of the quarterly sign off form.

Those sites who will send through the **data templates for upload**, we would appreciate this **1 week prior to the deadline date**.

Improving Patient Reports -Working group



We would appreciate your input on the additional information we can add to the individual patient reports.

Information provided in the ACFDR will give you a summary of the person variant and latest height, weight, lung function and hospitalisation. It also gives you a few graphs displaying the clinic measures taken over a specified time period.

Could you kindly provide a list of data points you would like to be able to view/summarised in the individual patient report that would be beneficial to your sites.

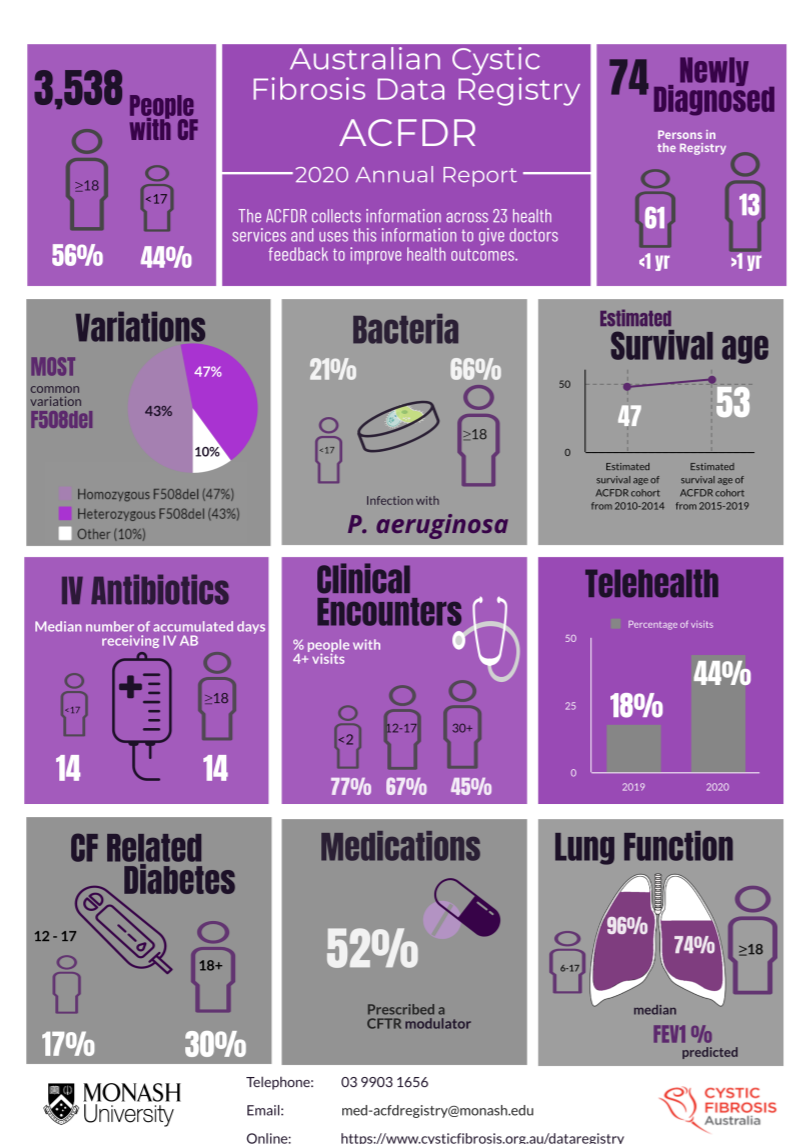
Please [ACFDR Help desk](#) on med-acfdregistry@monash.edu

Hot off the Press - 2020 ACFDR Annual Report

We are excited to announce that the ACFDR 2020 Annual Report has been published along with a new consumer-focused infographic. Printed copies will be circulated to your centre shortly.

The report and infographic have also been made available on the Cystic Fibrosis Australia website [here](#)

Please share these with your patients and their families and your clinic. We welcome any feedback you have.



Click [here](#) to download the Annual Report

Click [here](#) to download the infographic



2020 Site Reports

The Site reports have now been distributed to all the CF Centres, if you require another copy please contact Marisa at the [ACFDR Help desk](#) on med-acfdregistry@monash.edu.

This year along with the site reports, we have also included a list of any 'unknown' genotyping results that were generated from the reports. This will allow each site to update any pending data on their dashboard.

If you are unable to locate the genotype, you can select "other" from the drop-down menu and use free text.

Update to the Complications and Treatment Form

Covid 19 Vaccination, has now been added to the complications and treatment form, which will be included at the end of year sign off along with influenza and pneumococcal vaccinations.

Project Details

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You are receiving this newsletter due to your association with the ACFDR. Please forward this email onto colleagues or others interested in the registry.

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Australian Cystic Fibrosis Registry (ACFDR) - Newsletter

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