



Welcome to the ACFDR Newsletter

Issue #15

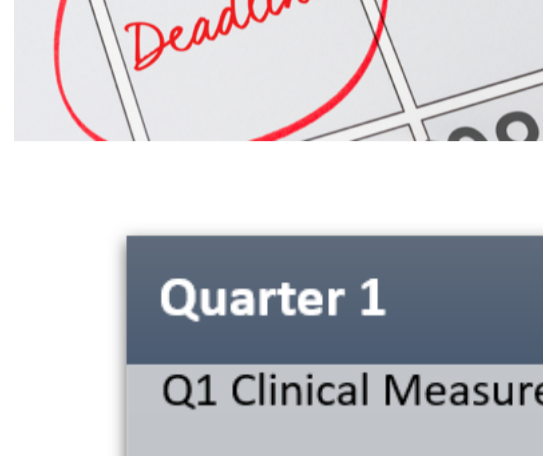
May 2022



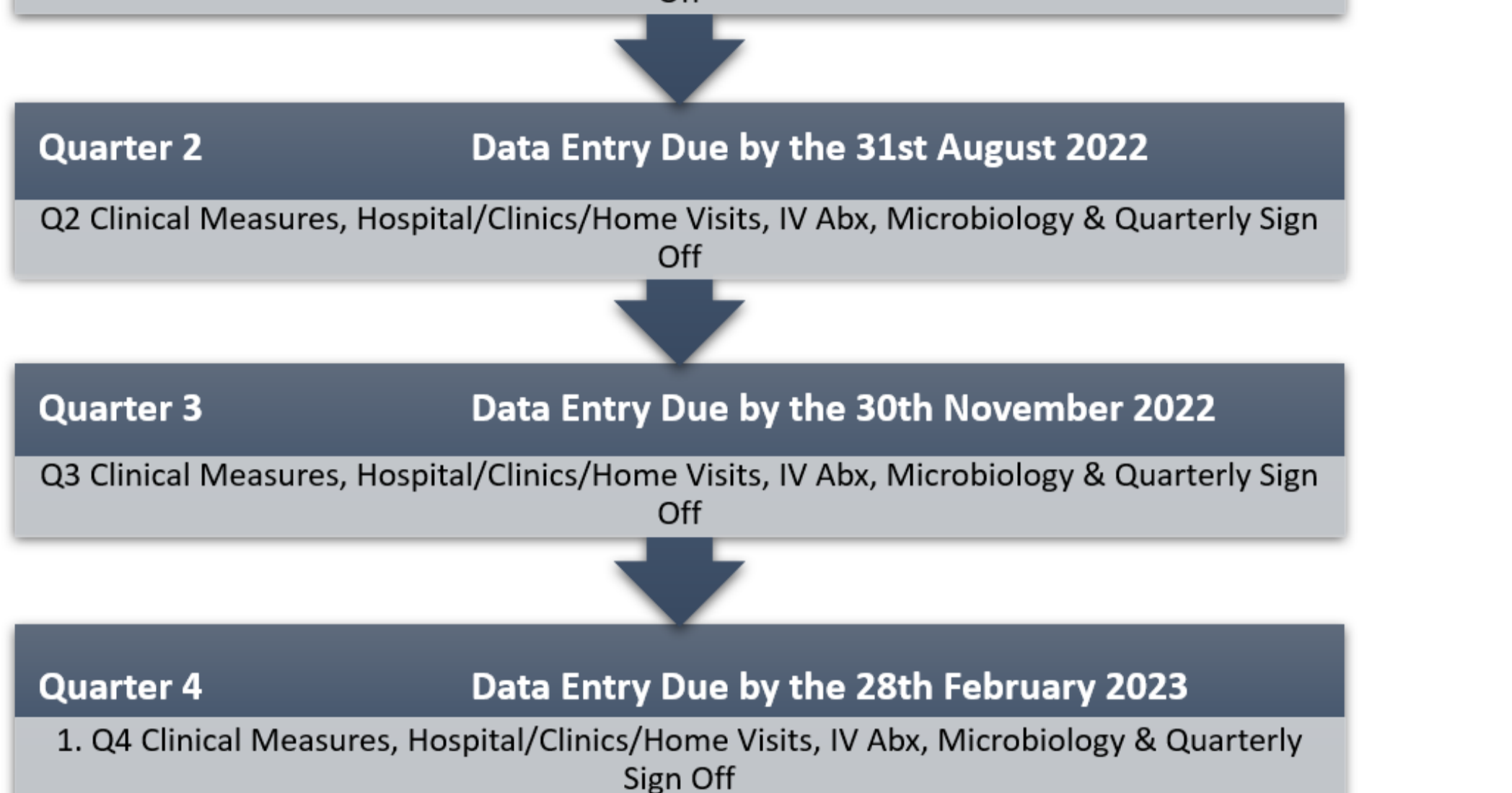
2021 Data Entry Complete

Thank you all for your continued dedication to updating the ACFDR each quarter. We are now collating the data for the 2021 Annual report.

Please keep an eye out for any emails from us, as we may reach out to you with data queries during this process.



2022 Data Entry Deadlines



Quarter 1 forms for 2022 data will be due 31st May 2022.

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

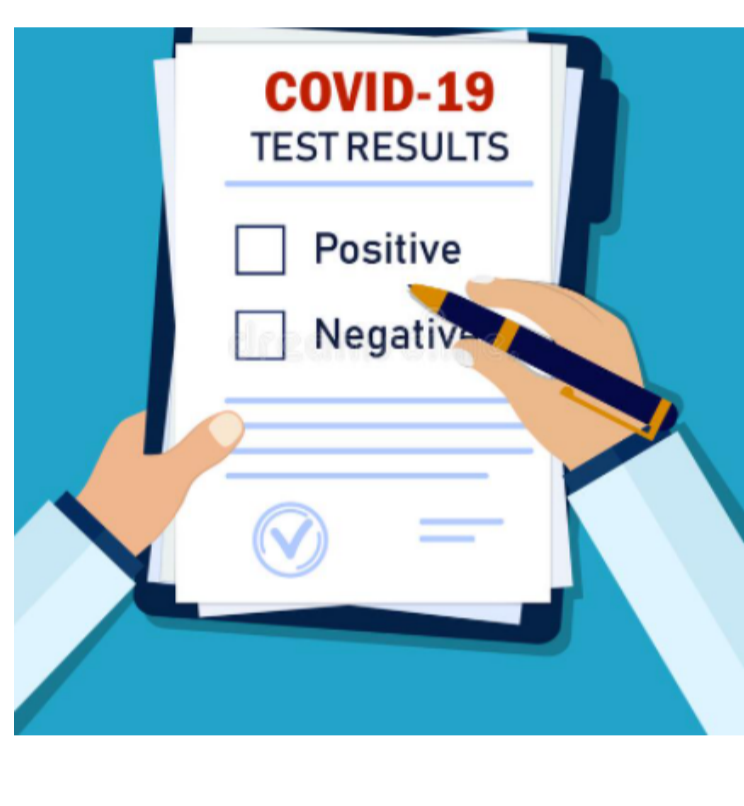
Those sites who will send through their data via templates for upload, we would appreciate this prior to the deadline date.

Don't forget to enter your Covid 19 Positive test results

The ACFDR are collecting data from the sites for an upcoming international Covid 19 study; Global impact of COVID-19 in cystic fibrosis

The Global CF Registry Harmonization Group mobilised to monitor the disease course amongst people with CF in near to real time. The group membership has now reached 22 countries and has produced two conference posters and four peer-reviewed publications in two years, with another publication forthcoming.

The ACFDR is not receiving any funding for collaborating on this project, and we are grateful for all of the support of those centres that we have contacted to enter details of patients with covid positive results.



Updates to ACFDR Questions

In response to feedback from sites, the Steering Committee members have decided to streamline the Covid 19 Vaccination and Mental Health questions in the Annual Complications and treatment form.

Did the patient have a Covid 19 vaccination during this calendar year? Yes No Not known

Which dose has been administered 1st dose 2nd dose 3rd dose 4th dose

You will no longer be required to record the vaccination brand or date, and we have included the option for the 3rd and 4th boosters.

Mental Health

Has a mental health screen using GAD-7 and PHQ-9 been performed during this calendar year? Yes No Not known

Was a high score received for either questionnaire? Yes No Not known

Has the patient engaged with a mental health service provider during this calendar year? Yes No Not known

The branching logic has now been removed for the mental health question, so it can be recorded if a psychology review has occurred without first selecting GAD-7 /PHQ-9

Colonoscopy presentations

There is now an option to add colonoscopy to the reason for participants entering the hospital for a day procedure. This will be recorded in the "other primary reason" field.

Hospital/clinic visits & Home IV Ab events

Event: Q1 Jan-Mar

Event Clinic visit Hospitalisation IV Home Therapy Both IV hospitalisation and IV Home

Hospitalisation Admission Type General Ward Admission ICU/Critical Care Admission Other

Primary reason for hospitalisation Respiratory related Gastro-intestinal related Other reason (incl. non-transplant surgery) Reason unknown

Other primary reasons for hospitalisation Dehydration CFTR medication administration Non-transplant surgery (includes outpatient surgeries) Transplant related Sinus infection Colonoscopy Other reason, specify Other reason, not specified

Individual Patient Reports

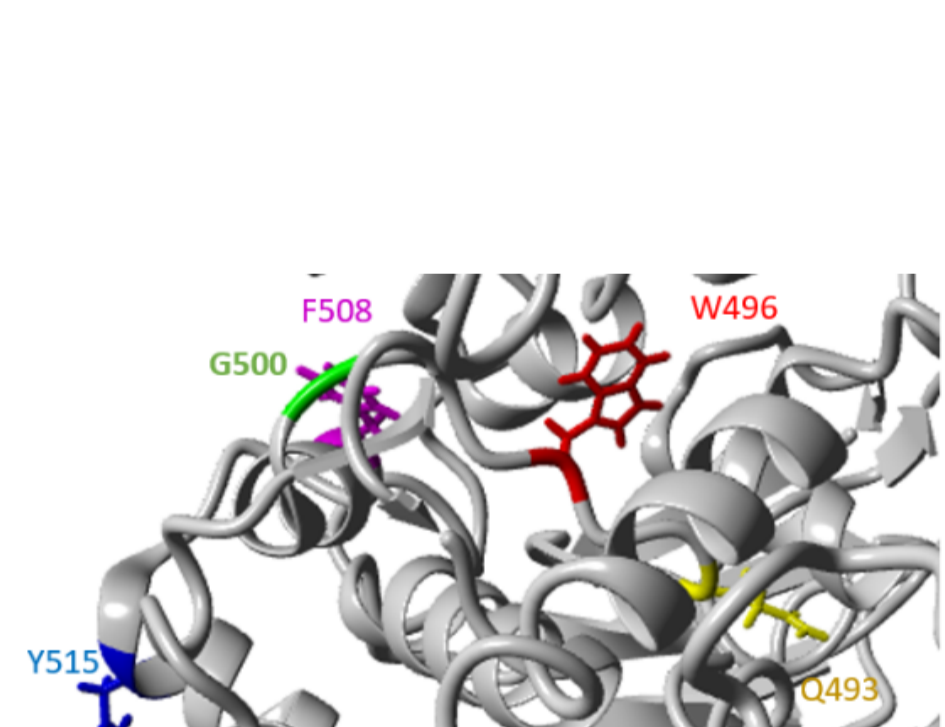
Positive Microbiology results have been added to the Individual Patient Reports.

When you hover over the results with a speech bubble, you will be provided with additional information from the Microbiology form.



Test Date	Test Type	P. aeruginosa	H. influenzae	S. capensis complex	S. aureus	MRSA
10-03-2020	Induced					
30-03-2020	Induced					
04-04-2020	Induced					
31-08-2020	Sputum					
26-10-2020	Induced					
30-11-2020	Induced					
09-12-2020	Induced					
19-04-2021	Induced					
02-08-2021	Induced					
15-08-2021	Induced					
16-08-2021	Induced					
31-10-2021	Induced					

19 Variants added



We have added 19 CF variants to the ACFDR list, in accordance with the latest information received from John Hopkins University, and the ACFDR now holds the most up to date information.

Did you know you can type part of the variant directly into the data field and all matching variants will pop up, instead of scrolling through the list? This will minimise the use of the "other" field.

GENETIC MUTATION DETAILS

Was genotyping undertaken? Yes No Not known

Date of genotype not collected (prior to new database) Yes

Genetic mutation 1 F508del--- p.Phe508del--- c.1521_1523delCT

Genetic mutation 2 p67L

Other mutation 2 P67L--- p.Pro67Leu --- c.200C>T

Genetic mutation 3 P67L



Transfer/Shared Records

Shared/transfer records – To limit any duplicate entries in the registry please feel free to contact the [ACFDR Help desk](#) at med-acfdregistry@monash.edu to clarify if a person is already in the registry or to receive any guidance.

Notice any Mismatches?
Get in contact with us if you notice any errors, we're here to help keep the data clean and up to date.

Project Details

Project Leads

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Our mailing address is: Australian Cystic Fibrosis Data Registry, School of Public Health and Preventive Medicine, Monash University, 553 St Kilda Road, Melbourne, Victoria 3004, Australia

