



Our Annual Report is Almost Here

We are in the final stages of compiling the **2021 ACFDR Annual Report**, we thank you all for your contribution to entering the data into the registry and look forward to getting the report out to you soon!

2022 Data Entry Deadlines

Quarter 3 forms for 2022 data will be due on 30th November 2022.

This includes all clinical measures, hospital/clinic visits/ microbiology and completion and the quarterly sign-off form.
 For those sites that will send through their **data via templates** for upload, we would appreciate this **prior to the deadline date**.



ACFDR Funding Update

Please note due to limited funding available to the ACFDR, Marisa has been deployed to work on other projects within Monash University. However, she will still be working on the registry 2.5 days per week. Please bear with us as we are currently limited in our resources.

Continue to send any queries to the ACFDR helpdesk email,
med-acfdregistry@monash.edu



Pilot to Improve Data Capture in the ACFDR

In order to improve data capture in the ACFDR, we have been given approval by the ACFDR Steering Committee to pilot modified quarterly data payments.

Quarterly payment will be determined by the presence or absence of clinical data in the remaining quarters for 2022.

For the next period of data capture (Q3 and Q4 2022), payment is allocated to those records with quarterly clinical data available.

The rationale is to incentivise all sites to capture any data performed in the quarter, in order to maximise data completeness in the ACFDR. The pilot audit performed, showed some inconsistencies with missing data compared to what was present in the electronic medical record.

| Data Collection Instrument | Core Data | Q1 Jan-Mar | Q2 Apr-Jun | Q3 Jul-Sep | Q4 Oct-Dec | Annual Data |
|--|-----------|------------|------------|------------|------------|-------------|
| Registration | ● | | | | | |
| Demographics | ● | | | | | |
| Initial Diagnosis | ● | | | | | |
| Sweat tests (post diagnosis) | ○ | | | | | |
| Genetic mutation results (post diagnosis) | ● | | | | | |
| Pancreatic insufficiency (post diagnosis) | ○ | | | | | |
| Clinical measures | | ● | ○ | ○ | ○ | |
| Hospital/clinic visits & Home IV Ab events | | ● | ○ | ○ | ○ | |
| Microbiology | | ○ | ○ | ○ | ○ | |
| Quarterly sign off | | ● | ○ | ○ | ○ | |
| Complications And Treatment | | | | | | ● |
| CFTR modulators | ○ | | | | | |
| Transplants | ○ | | | | | |
| Annual General update and sign off | | | | | | ● |
| Delete all data on event: | × | \$20 | \$20 | \$20 | \$0 | \$30 |

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|--|-----------|------------|------------|
| Registration | ● | | |
| Demographics | ● | | |
| Initial Diagnosis | ● | | |
| Sweat tests (post diagnosis) | ○ | | |
| Genetic mutation results (post diagnosis) | ● | | |
| Pancreatic insufficiency (post diagnosis) | ● | | |
| Clinical measures | | ○ | ○ |
| Hospital/clinic visits & Home IV Ab events | | ○ | ○ |
| Microbiology | | ○ | ○ |
| Quarterly sign off | | ○ | ○ |
| Complications And Treatment | | | |

Please complete the clinical measure form, visits/IB Ab from and the microbiology form before completing the sign-off for the Quarter.

This sign-off form acts as a final check for the quarter to ensure no clinical data is left out of the quarter.

Physiotherapy Surveys in the ACFDR

A proposal to the ACFDR SC for the database to include physiotherapy items as a separate module in the registry has been put forward.

CF physiotherapists will be responsible for collecting survey data during routine outpatient appointments and then entering the airway clearance techniques and physical activity data into the database.



Keep an eye out for our newsletter for any further updates

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.