



# ACFDR

AUSTRALIAN CYSTIC  
FIBROSIS DATA REGISTRY

## APRIL 2023 REGISTRY UPDATES



### 2023 Data Entry Deadlines

**Quarter 1 2023** data entry will be due on **31st May 2023**. This includes all **clinical measures, hospital/clinic visits/ microbiology and completion of 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.*

#### Quarter 1

#### Data Entry Due by the 31st May 2023

Q1 Clinical Measures, Hospital/Clinics/Home Visits, IV Abx, Microbiology & Quarterly Sign Off

#### Quarter 2

#### Data Entry Due by the 31st August 2023

Q2 Clinical Measures, Hospital/Clinics/Home Visits, IV Abx, Microbiology & Quarterly Sign Off

#### Quarter 3

#### Data Entry Due by the 30th November 2023

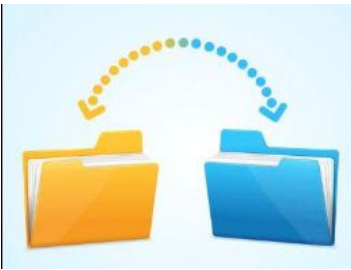
Q3 Clinical Measures, Hospital/Clinics/Home Visits, IV Abx, Microbiology & Quarterly Sign Off

#### Quarter 4

#### Data Entry Due by the 29th February 2024

1. Q4 Clinical Measures, Hospital/Clinics/Home Visits, IV Abx, Microbiology & Quarterly Sign Off

2. 2023 Annual General Update/Sign Off, Complications & Treatment.



## New/Transfer/Shared Records

If a patient has been diagnosed quite some time ago, there is a possibility this is **not a new patient** to the registry. There may be a historical record from your clinic or a transferred patient.

To limit the duplicate entries in the registry please contact the ACFDR Help desk at [med-acfdregistry@monash.edu](mailto:med-acfdregistry@monash.edu) to clarify if a person is already in the registry and receive guidance before entering a new record.

## Adding in Retrospective Patient Reviews?

We have noticed there are quite a few older patients being added back to the registry, it is important that you also go back and update all the previous survey year data you have on this patient. Please reach out if you require any clarification.

Q1 Jan- Mar	Q2 Apr- Jun	Q3 Jul- Sep	Q4 Oct- Dec	Annual Data
\$20	\$20	\$20	\$0	\$30
●	●	○	○	
●	●	●	○	
○	●	●	○	
●	●	●	●	
				●
				●

## Upcoming Site Payments

This a reminder that quarterly payment will be determined by the presence or absence of clinical data in the 2023 quarters. **Payment is allocated to those records with quarterly clinical data available.** The rationale is to maximise data completeness in the ACFDR.



## Identified Data Amendment

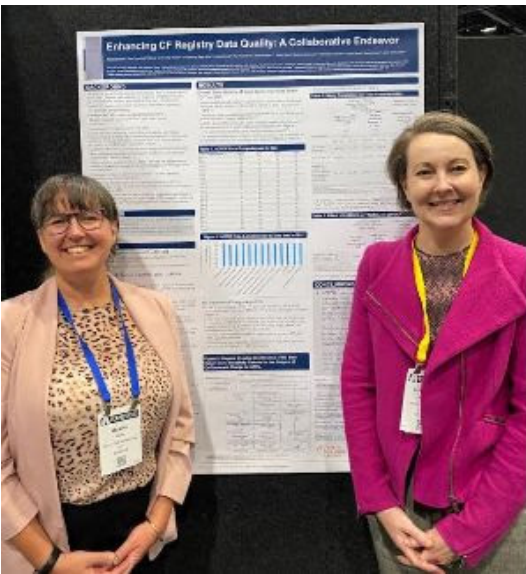
After a successful pilot, the ACFDR Steering Committee members have agreed to move forward with rolling out incorporating identified data throughout all Australian CF centres.

This will include the addition of the **full given and surname, address, phone number, and email address.** The amendment has been approved by the Lead Alfred HREC and we are now reaching out to your local government officials to implement the

same. Once local governance approval has been received we will provide your centre with the updated documentation

***We now have 6 CF centres participating in the collection of Identified data, 90% of patients who have been approached have agreed to the inclusion of identifiers in the registry. So far over 11% of all ACFDR patients nationally, have been contacted for the inclusion of identified data.***

**We appreciate your assistance in progressing this amendment through your local governance offices.**



### **TSANZ conference in Christchurch NZ**

Professor Susannah Ahern together with Dr Maxine Orr, Vertex Pharmaceuticals presented at the Thoracic Society of Australia and New Zealand (TSANZ) conference in Christchurch NZ in March 2023.

Read the abstract [here](#)



### **Monash University REDCap Security Update**

The ACFDR is managed on a secure Monash University platform that has been reviewed by the Monash Cyber Security team. The Monash REDCap is hosted on-prem securely at a Monash Data Centre in Australia and uses multi-factor authentication for application access. *The platform is continuously uplifting its security requirements in line with Monash University's cyber security advice.*

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## **Project Details Project**

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Project Contacts

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*You are receiving this newsletter due to your association with the ACFDR.*

*Please forward this email to colleagues or others interested in the registry*

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