



# ACFDR

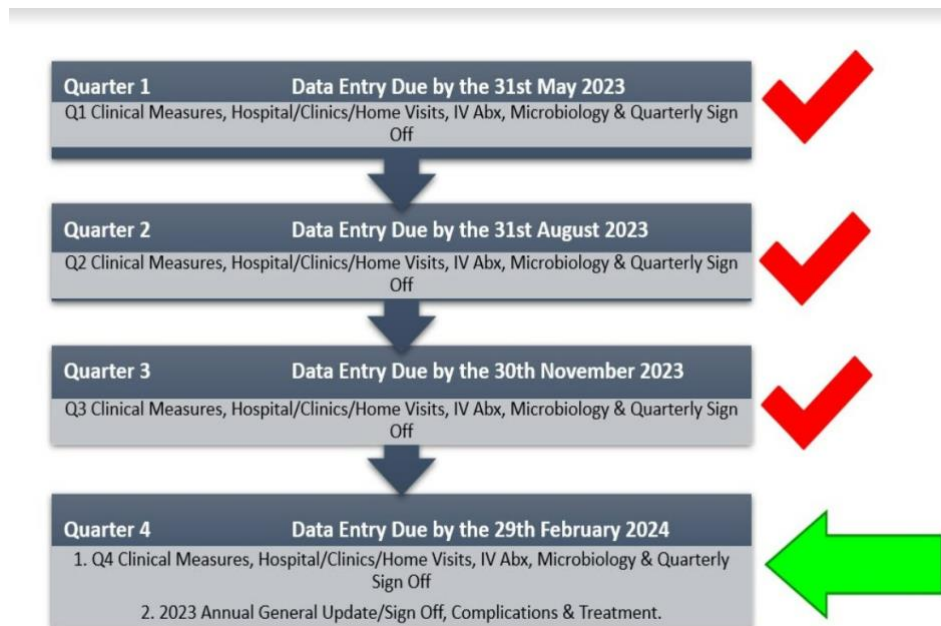
AUSTRALIAN CYSTIC FIBROSIS DATA REGISTRY

## DECEMBER 2023 REGISTRY UPDATES



### 2024 Data Entry Deadlines

The deadline for **Quarter 4, 2023 data entry is February 29, 2024**. Ensure all clinical measures, hospital/clinic visits, microbiology, and the quarterly sign-off form are completed by this date. Prompt completion of Q4 data is crucial, as we will immediately commence compiling the 2023 Annual Report. Please be mindful of timelines, considering holiday breaks. Not meeting the Q4 data entry deadline could lead to exclusion from the 2023 annual report



### UPDATED ACFDR REDCap Login

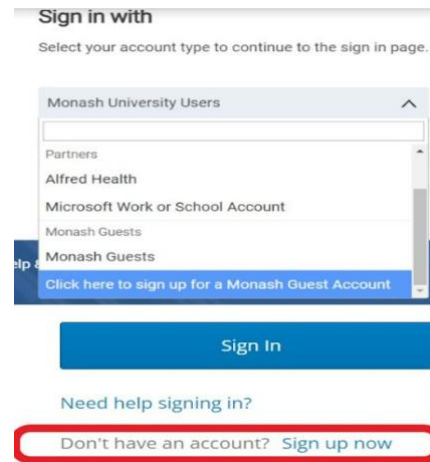
All REDCap users will be required to use the BLUE REDCap login (SSO/OKTA) to access the ACFDR database by December 2023. As the old login will be no longer in use. Below are the instructions for your new login process.

Click **Login with SSO/OKTA** to access Monash REDCap.

Log in method **Login with SSO/OKTA**

1. Please log in with the MONASH GUEST ACCOUNT - if this is your first time using this method-please select "**click here to sign up for Monash Guest account**" from the drop-down menu.

2. Select "**Sign up now**" on the next page - please use your work email address to register for the Monash Guest login account.



3. Please email us at **med-acfdregistry@monash.edu** if you require any assistance with this process.

## Identified Data Amendment

Following our last ACFDR Steering Committee meeting, we have made updates to the Master Patient Information Consent Forms (PICF) for opt-in consent centres, along with corresponding changes to the Explanatory Statements for the opt-out model of consent centres. We wanted to provide a summary of these changes for your information;



### Summary of Changes:

New participants have the option to join the registry with de-identified data, maintaining the minimum requirements of 2 initials of the given name and surname, date of birth, and gender.

Inclusion of the Individual Health Identifier (IHI), as outlined in the Department of Health contract <https://www.servicesaustralia.gov.au/individual-healthcare-identifiers>

### Discussion Highlights:

During our last ACFDR Steering Committee meeting, it was emphasised that the Master Ethics documents must reflect a participant's option to consent to the use of identifiers, specifying the various identifiers that may be collected.

Demographic information, including the Individual Health Identifier, full name, sex, date of birth, address, email address, and phone number, may be collected. However, participants also have the flexibility to join the registry with the minimum demographic information requirement of 2 letters of their surname and given name, date of birth, and gender.

The discretion to determine which identifiers to include on their PICF lies with the treating CF clinical centre/participants. The Master documents will encompass all identifier options, however, each CF centre/participant will have the option to select their preferred identifiers through local governance applications.

---

## 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

---

## Happy Holidays

The ACFDR team will be taking a break over the holiday season. Our office will be closed from Thursday 21st December 2023 until Monday 1<sup>st</sup> January 2024. We wish you all a happy and safe holiday season and are looking forward to an exciting new year



---

### Project Details Project

Academic Lead

**Prof Susannah Ahern**

Clinical Lead

**Prof Peter Wark**

Deputy Clinical Lead

**Andre Schultz**

### Project Contacts

Marisa Caruso - Registry Coordinator

T: (03) 9903 1656 E: [med-acfdregistry@monash.edu](mailto:med-acfdregistry@monash.edu), [marisa.caruso@monash.edu](mailto:marisa.caruso@monash.edu)

Dr Rasa Ruseckaite - Senior Research Fellow & Deputy Monash Academic Lead

T: (03) 9903 0437 E: [Rasa.ruseckaite@monash.edu](mailto:Rasa.ruseckaite@monash.edu)