

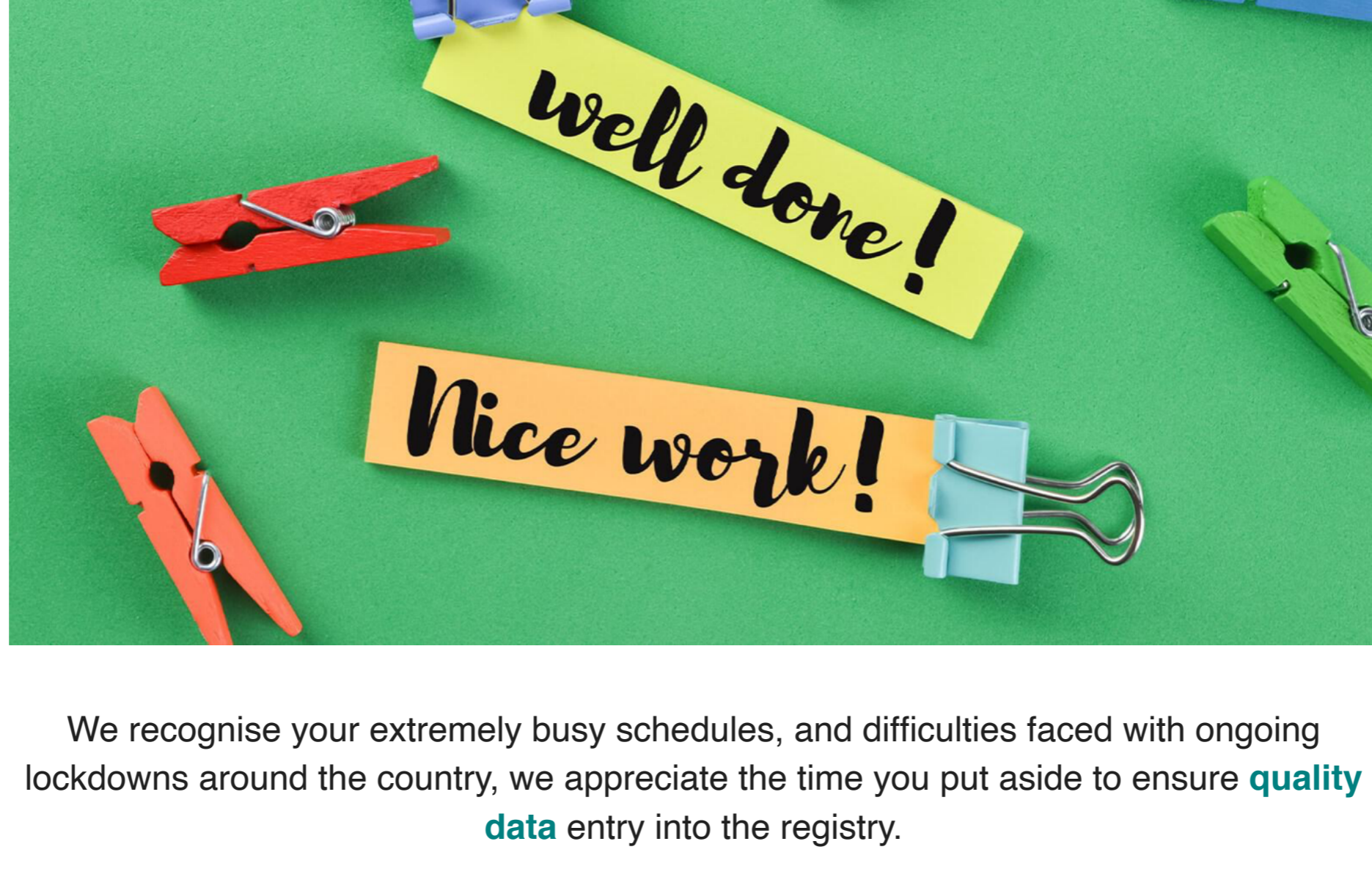
View this email in your browser



Welcome to the ACFDR Newsletter

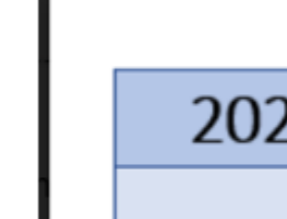
Issue #13

October 2021



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.

The ACFDR Team would like to say a huge thank you to all of you for your continuous dedication and hard work, it does not go unnoticed.



2021 Data Entry Deadlines

Table with 2 columns: 2021 Data Entry Required, Deadline for payment. Rows include Q1 2021 (31st May 2021), Q2 2021 (31st August 2021), Q3 2021 (30th November 2021), and 1. Q4 2021, 2. 2021 Annual Data, Complications and treatment. (28th February 2022)

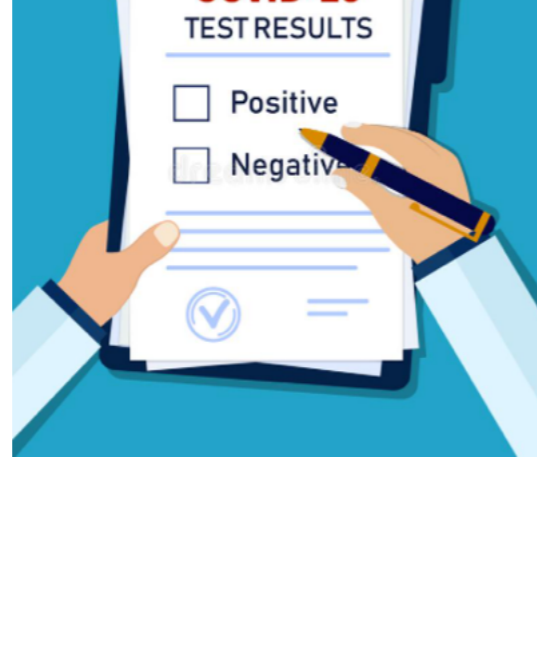
Quarter 3, 2021 data entry will be due on 30th November 2021.

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

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

Positive Covid Test Results

While fortunate that there are small numbers of Covid Positive results amongst the Australian CF community, it is important that these small numbers of are recorded in the ACFDR.



Please ensure any POSITIVE Covid Results from the beginning of the pandemic, are recorded in the Microbiology form.

If you have any queries or require assistance, please contact Marisa at the ACFDR Help desk on med-acfdregistry@monash.edu or 0421 105 755

Updated 2021 Minimum Data Set (MDS)

As per our last Steering Committee Meeting, the MDS has been updated. The Annual General Update and Sign off and the Complications and Treatment forms will need to be completed in full in order to receive payment.

Click on this link to obtain the PDF version of the updated MDS.

Table 1: 2021 per patient MDS for payment

Table with 3 columns: 2020, Form, Data items for per person payment. Rows include Core Data (Registration, Demographics, Initial Diagnosis, Sweat tests, Genetic Mutations, Pancreatic insufficiency, CFTR Modulator, Transplants), Quarterly data (Clinical Measures, Hospital/clinic visits, Microbiology, Quarterly sign off), and Annual Data (Complications & Treatments, Annual General update and sign off).

Updates to the Complications and Treatment Form

The Steering Committee has reviewed and made changes to the Annual forms that will be due for submission along with the Q4 data in February 2022. Please familiarise yourself with the changes made to these questions below.

Reach out to us if you have any questions at the ACFDR Help desk on med-acfdregistry@monash.edu or contact Marisa on 0421 105 755

Treatment for CF Related Lung Diseases

Form showing treatment options for CF related lung diseases, including checkboxes for Oral corticosteroids, Macrolides, Inhaled antibiotics, Tobramycin use, and Colistin use.

Pseudomonas eradication has now been added as an option for Tobramycin and Colistin use.

Covid Vaccination

Vaccinations form with a red circle highlighting the question: Did the patient have a Covid 19 vaccination during this calendar year?

Covid 19 Vaccination, has been added to the list of vaccinations received, here you will be able to add the first and second dose information.

Vitamins, enzymes or salt replacement used

Form asking if patient received vitamins, enzymes or salt replacement therapy during the current year, with checkboxes for Pancreatic enzymes, Vitamin A, D, E, K, and Salt replacement.

Previously the question asked if salt tablets were used, the definition of salt replacement has been added to include salt tablets and prescribed salt replacement drinks.

Hepatobiliary dysfunction

Form asking if patient had hepatobiliary dysfunction during the current year, with checkboxes for Liver disease, cirrhosis, gall stones, etc.

The removal of 'abnormal liver function' and 'gall stones' as options. The reason for the removal of these is the Steering Committee felt the remaining options were a more robust, concrete outcome to collect in the data registry.

Bone mineral density

Form asking if patient had a DEXA scan during the current year, with a date picker and checkboxes for Normal, Osteopenia, Osteoporosis, etc.

Previously the question asked the BMD status and the date of the last scan as compulsory questions. As a DEXA scan is not collected each year, sites may be recording 3 years in a row that the last scan was in 2018. The question has changed to first ask if a DEXA scan was performed this calendar year, then if so, to please record the date/status.

Mental Health

Form asking if patient had a mental health screen using GAD-7 and PHQ-9 performed during the current year.

The mental health question now includes the use of the mental health screens GAD-7 and PHQ-9. This question will populate when the person reaches 12 years of age.

Additional Questions

Form asking if patient received a physiotherapy review or dietitian review during the last calendar year.

The addition of physiotherapy and dietitian review during the last calendar year has also been included in the complications and treatment form.

Updates to the Annual General Update and Sign Off Form

Social Detail - Employment Status

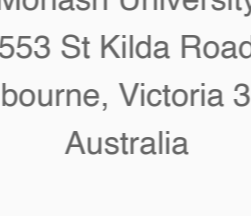
Form asking for last employment status provided and employment status for most of the time during the year.

The options for employment status have been changed to align with the international CF registries and the Australian Bureau of Statistics survey.

Project Details

- Project Leads: Academic Lead (Prof Susannah Ahern), Clinical Lead (Prof Scott Bell)
Project Contacts: Marisa Caruso - Registry Coordinator, Dr. Rasa Ruseckaite - Data Manager & Senior Research Fellow

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



Copyright © 2020 Monash University. All rights reserved. Australian Cystic Fibrosis Registry (ACFDR) - Newsletter

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

