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Welcome to the ACFDR Newsletter

<text>

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

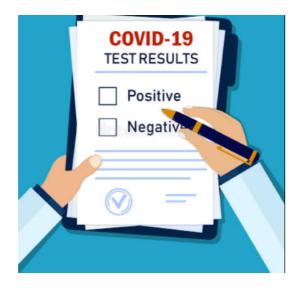
2021 Data Entry Required	Deadline for payment
Q1 2021	31 st May 2021
Q2 2021	31 st August 2021
Q3 2021	30 th November 2021
 Q4 2021 2021 Annual Data, Complications and treatment. 	28 th February 2022

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.

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 <u>ACFDR Help desk</u> on <u>med-acfdregistry@monash.edu</u> 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 <u>link</u> to obtain the PDF version of the updated MDS.

2020	Form	Data items for per person payment
	Registration	Entire form
	Demographics	Entire form
Core Data	Initial Diagnosis	2020 additional items: Diagnostic sweat test Pancreatic status Newborn details
	Sweat tests (post diagnosis)	Complete if updated data is available. If not: leave blank and confirm this in the Annual sign off form.
	Genetic Mutations (post diagnosis)	Complete if updated data is available. If not: leave blank and confirm this in the Annual sign off form.
	Pancreatic insufficiency	Complete if updated data is available. If not: leave blank and confirm this in the Annual sign off form.
	CFTR Modulator	Complete if on CFTR treatment. Leave form blank if not on CFTR treatment.
	Transplants	Leave form blank if no transplant history
Quarterly	Clinical Measures	Sections: 1. Date clinical measure taken 2. Weight and Height (one annual entry) 3. FEV1 (quarterly entry) - Enter best value per quarter
data	Hospital/clinic visits & home IV AB events	Clinic Visits
	Microbiology	Entire form
	Quarterly sign off	Entire form
	Complications & Treatments	Entire form
Annual Data	Annual General update and sign off	Entire form

Table 1: 2021 per patient MDS for payment

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 <u>ACFDR Help desk</u> on <u>med-acfdregistry@monash.edu</u> or contact Marisa on 0421 105 755

Oral corticosteroids Treatment for CF related lung disease during this calendar year 🕖 🗌 Macrolides * must provide value Inhaled antibiotics Regular oral antibiotic use Antifungal triazoles □ No treatment during the calendar year 🗌 Not known Select all that apply Tobramycin 🗹 Colistin Inhaled antibiotic type Other inhaled antibiotic, specify * must provide value Inhaled antibiotic not specified Select all that apply Continuous Interrupted (e.g. month on/off) Short term (e.g. exacerbations) Tobramycin use Pseudomonas eradication

Treatment for CF Related Lung Diseas



Not specified

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

Covid Vaccination

	Vaccinations		
	Did the patient have an influenza vaccine during this calendar year? * must provide value	[®] ○Yes ○No ○Not known	reset
	Did the patient have a pneumococcal vaccination during this calendar year? * must provide value	⊖ O Yes O No O Not known	reset
\langle	Did the patient have a Covid 19 vaccination during this calendar year? * must provide value	🖯 Yes O No O Notknown	reset

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

GASTROINTESTINAL AND HEPATIC TREATMENT AND COMPLICATIO	NS REQUIRED DURING THE CURRENT YEAR
Did the patient receive vitamins, enzymes or salt replacement therapy during this calendar year? * must provide value	[⊕] ● Yes ○ No ○ Not known
Vitamins, enzymes or salt replacement used * must provide value	 Pancreatic enzymes Vitamins A, D, E, K Salt replacement (salt tablets, prescribed salt replacement drinks) Select all that apply

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.

Gall stones, requiring surgery/procedure

🗌 Not known

Please select all that apply

* must provide value

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

Bone mineral density	
Was a DEXA scan performed during this calendar year? * must provide value	🛞 💿 Yes 🔿 No 🔿 Not known
Date of most recent DEXA scan * must provide value	H D-M-Y
Bone mineral density status * must provide value	 Normal (>-1SD) Osteopenia (< -1to - 2.5 SD for hip/spine) Osteoporosis (< -2.5 SD and/or fracture for hip/spine) Not known

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

Mental Health		
Has a mental health screen using GAD-7 and PHQ-9 been performed during this calendar year?	🕒 💿 Yes 🔿 No 🔿 Not known	rese
Was a high score received for either questionnaire?	O Yes O No O Not known Definition of a high score equals >10	rese
Has the patient engaged with a mental health service provider during this calendar year?	🕒 🔿 Yes 🔿 No 🔿 Not known	rese

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

Additional Questions

Physiotherapy Review		
Did the patient receive a physiotherapy review during this calendar year?	⊖ ⊖Yes ⊖No ⊖Not known	rese
Dietician Review		
Did the patient receive a dietician review during this last calendar year?	🛞 🔿 Yes 🔿 No 🔿 Not known	res

The addition of physiotherapy and dietician 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

Last employment status provided:		
Employment status (for most of the time during the year)	 Employed full time Part time Full time homemaker Disability support/Pensioner Retired Student Unemployed Not known 	eset

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

Project Contacts Marisa Caruso - Registry Coordinator T: 0421 105 755 E: med-acfdregistry@monash.edu, marisa.caruso@monash.edu
Marisa Caruso - Registry Coordinator T: 0421 105 755 E: med-acfdregistry@monash.edu,
T: 0421 105 755 E: med-acfdregistry@monash.edu,
E: med-acfdregistry@monash.edu,
marisa.caruso@monash.edu
Dr. Rasa Ruseckaite - Data Manager & Senior
Research Fellow
T: +61 (0)3 9903 0437 E: Rasa.ruseckaite@monash.edu
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