

SIS Data Entry Guidelines for Cystic Fibrosis Centers

The SIS data entry guidelines below are a supplement to the Screening Information System (SIS) Training Manual (Chapter 2.3: Description of CFC Follow-Up Activities) that you have already received and a replacement for the SIS Data Entry Guidelines previously emailed to you.

Please use the information in this document as a guide for entering data into the following SIS screens:

- Cystic Fibrosis Service Report (CFSR)
- Confirmatory Test Results (for Sweat Test results ONLY)
- Case Notes

General Guidelines

In general, please complete as many fields as possible in the CFSR and Confirmatory Test Results screens. In the Case Notes screen, please enter any additional information that is needed to augment or clarify the information in the CFSR. The guidelines below describe in detail how we would like the data entered for a selection of the fields in each of these screens.

Timeliness of Data Entry

As stated in the vendor agreement scope of work, a CFSR should be completed as soon as possible (preferably within 1 business day and no later than 5 calendar days) after each significant contact with the patient.

Questions

- If you have any questions about how to enter data into SIS, please contact Ruth Koepke with the Genetic Disease Screening Program by phone (510-412-1471) or email (ruth.koepke@cdph.ca.gov).
- If you are having problems logging into SIS, please contact the Help Desk by calling 510-307-8928.

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Cystic Fibrosis Service Reports

When should a CFSR be completed?

- Complete a new CFSR after each significant contact with the patient, the patient's family, the patient's primary care provider, or other health care provider managing the care of the child. Significant contacts may be face to face, by phone, by email or by fax.
- A CFSR should be completed for each significant contact from the initial patient referral through resolution of disease status and treatment initiation.

Guidelines for completing selected fields in the CFSR

Field Name	Data Entry Guidelines
CF Foundation Patient ID	Please do not check the box for 'Not enrolled in patient Registry' until after you have discussed this with the parents and they have declined to enroll their child in the registry. We understand that this may take 1-2 months to be completed.
Case Status	<p>Note: Once a CFSR has been saved, the Case Status cannot be changed. To avoid saving the incorrect Case Status: (1) Click off of the Case Status dropdown list before using the scroll-down function on your mouse and (2) Double-check your entry in the Case Status field before saving the CFSR.</p> <p>Use the guidelines below to choose the appropriate Case Status for each CFSR:</p> <p><u>Pending:</u> Keep the Case Status as <u>Pending</u> until the sweat test results and other test results have been entered into SIS <u>and</u> indicate a Resolution of CF, Suspect CF, or No Disorder according to the sweat test interpretation grids in the <i>Minimum Guidelines for the Follow-Up of Newborns with Positive Cystic Fibrosis Newborn Screening Results</i>.</p> <p><u>Resolved - No Disorder, Cystic Fibrosis, Suspect Cystic Fibrosis:</u> Choose these options only after the appropriate number of sweat test have been conducted, entered into SIS, and indicate a Resolution as detailed in the sweat test interpretation grids in the <i>Minimum Guidelines</i>.</p> <p><u>Newborn expired before follow-up:</u> Choose this option if the infant expires before a diagnosis has been confirmed.</p> <p><u>Lost to follow-up:</u> Choose this option if the infant's family cannot be located or contacted.</p> <p><u>Parent refused follow-up:</u> Choose this option if the infant's parents refused to follow-up with the CF Center.</p> <p><u>No response from parent:</u> Choose this option if the parents did not respond to a request to follow-up this infant.</p>

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	<u>Transferred</u> : Choose this option if the patient is transferred to a different CF Center.
Meconium ileus after birth	Please choose 'Yes' from the drop-down menu if the newborn was diagnosed with meconium ileus in the first month of life.
Mother and Father	Please enter the race/ethnicity for each parent and the height for each parent. If genetic testing was done, enter the CFTR mutations identified for each parent.
Other Treatment	If RSV immunoprophylaxis is given, check the box for the field Other Treatment and after the word specify type the brand (e.g., 'Synagis').
Global Health Assessment	Please complete this field each time you complete a CFSR. The option 'Not seen yet' is available at the bottom of the dropdown list.

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Confirmatory Test Results (for Sweat Chloride Test results ONLY)

How should Sweat Chloride test results be entered into SIS?

- Sweat Cl test results should be entered into the Confirmatory Test Results section in SIS.
- The sweat Cl test results should be entered into SIS before the CFSR Case Status is changed to Resolved – Cystic Fibrosis, Suspect Cystic Fibrosis or No Disorder.
- Every sweat Cl test conducted should be entered, even if the quantity was not sufficient.
- Only sweat Cl test results should be entered into the Confirmatory Test Results section. All other test results should be documented in the CFSR (or Case Notes if you are not able to document the information in the CFSR).

Guidelines for completing fields in the Confirmatory Test Results screen

Field Name	Data Entry Guidelines
Test Type	Choose 'CF Sweat CL' from the drop-down menu.
CF Sweat Test Lab Name	Choose from the drop-down menu the name of the laboratory where the sweat chloride test was conducted.
Result	<p><u>Highest Result Without Units:</u> In the Result field, enter the value of the test result <u>without</u> the units. For example, for a sweat Cl test with the result 96 mEq/L, enter the value '96'. If the sweat Cl results from the two arms are different, please enter the <u>highest</u> result. For example, if the result from one arm was 97 and the result from the other arm was 95, enter the result as '97'.</p> <p><u>QNS Results</u> If the sample was QNS, please enter the Result as 'QNS'.</p>
Comments	<p><u>Results with units:</u> Enter the value of the sweat Cl result for each arm AND the units in the Comments field. Using the example above, you would enter 'Sweat Cl Test Results: 97 and 95 mEq/L'.</p> <p><u>Sample Weight:</u> If it is available, enter the weight of the sample tested in the Comments field (e.g., 'Sample weight: 145 mg').</p>
Reference Range	Please enter the reference range for the test (e.g., '<40 mEq/L = Normal')

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Case Notes

What information should be entered into the Case Notes?

- After the patient has been diagnosed, please enter:
 - Date of diagnosis
 - Enter the date that the clinical diagnosis of Cystic Fibrosis or Suspect Cystic Fibrosis was made for the patient. In some circumstances, this date may be before the sweat test was conducted.
 - Name of diagnosing physician
 - Date treatment initiated

- Additional information to enter:
 - Explanations for unusual delays in diagnosis
 - Plans for future visits/treatment with patient
 - Plans for future sweat testing
 - Date of next scheduled appointment
 - Changes to the patient's name
 - Any other information you think is important or interesting about the follow up of this patient