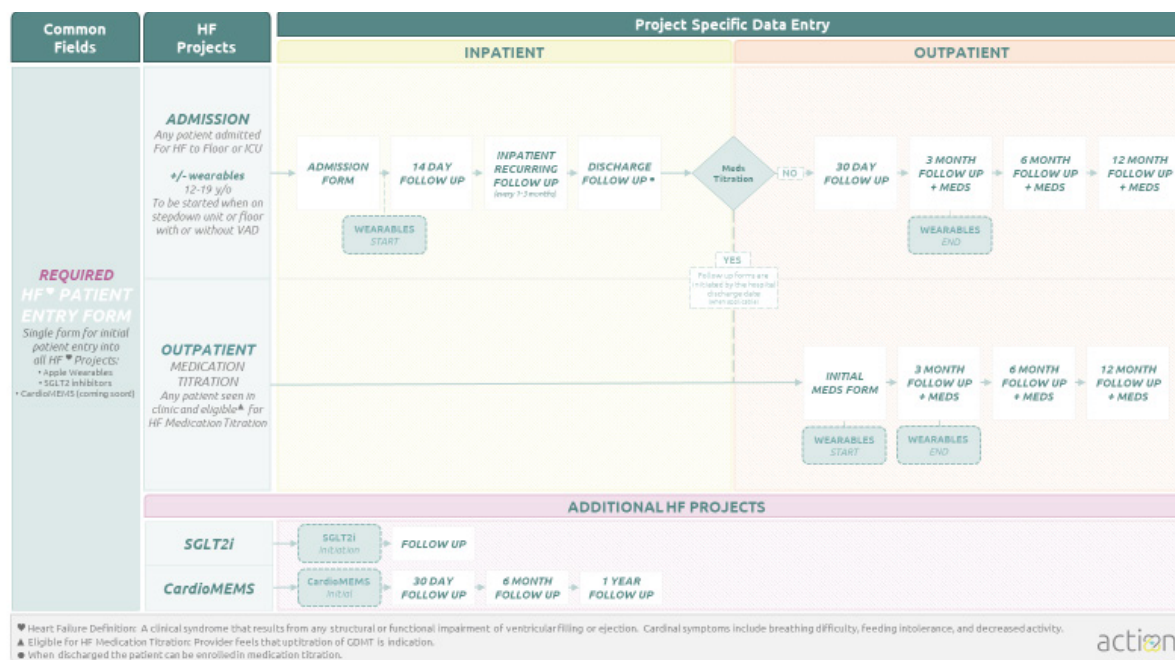


Heart Failure Registry

REDCap + Registry Summary



FAQs: Data Entry + REDCap

Q. Can I go back and alter which studies the subject is participating in?

- **Yes you can!** The "Entry" Form under "Enroll" is where you indicate which project you are going to fill out forms for. You can initially choose one or more projects at first (for example: a patient recently hospitalized), but go back later and participate in additional projects (example: you later decide to place a CardioMEMS or put the patient on an SGLT2-inhibitor).

Q. Am I supposed to enroll in both the hospitalization and outpatient medication titration projects?

- **No, do not** enroll in both. For a patient admitted/recently discharged from the hospital, please enroll using the "hospitalization data" option.
- If you are using the medication titration cards/spreadsheets after your patient has been discharged, there is a yes/no question to indicate this.
 - Please then select "NO" for enrolling the patient in outpatient medication titration.
 - Please only select "YES" for "Outpatient Medication Titration Project" if enrolling the patient from outpatient clinic.

Q. What if they are enrolled in "Outpatient Medication Titration Project", but then get admitted?

- Return to the "Entry" Form under "Enroll" and indicate the patient has been hospitalized in the "ACTION Projects" section. This will now permit you to fill out the Admission Form.
 - From now on, the timeline for your patient will follow the hospitalization discharge follow up. You will NOT have to continue filling out forms (3 month, 6 month, etc.) for the Outpatient Medication Titration Project. Instead, you will fill out the 'after discharge' follow up forms (3 month, 6 month, etc.). This will be readily apparent to you on your dashboard if you have selected that the patient is admitted.

Q. What do I enter for medications at Admission?

- This question is specifically seeking to capture if your patient was on any medications to improve or manage the signs/symptoms of decreased heart function or heart failure prior to the admission. Please select “No” if your patient was NOT on heart failure medications prior to admission.
- *Example: If your patient is a 4 month old presenting for the first time with newly diagnosed dilated cardiomyopathy and acute decompensated heart failure, please select “No”. If your patient has been known to have impaired systolic function and has been on enalapril for 3 years, then please select “Yes” and complete the medication section below.*

Q. What date to I put for “Admission” if diastolic or systolic impairment or signs/symptoms of heart failure were diagnosed AFTER the patient was already admitted?

- Enter the date that your team “diagnosed” or started to use medications for decreased heart function and/or heart failure. There is place to indicate this on the Admission Form. Do NOT put in the date of admission in these cases.

Q. What should I put for the quantitative or qualitative heart function if a range was given in the echocardiogram report?

ex: “mild-to-moderate dysfunction”

- Please aim to be consistent within your site in how you choose to answer this question. We suggest consistently choosing the more severe end of the range (example: choose “moderate” if the report is “mild-to-moderate”. Please feel free to add a comment that it was a range.

Q. How do I add a comment in REDCap?

Is the patient receiving ongoing care for any of the following?
(choose all responses that apply)
* must provide value

☐ Chronic kidney disease

☐ Chronic lung disease (on home oxygen, on positive pressure ventilation, on airway clearance regimen, etc.)

☒ Neurological disease (epilepsy/seizure disorder, sequelae of stroke)

☐ Chronic liver disease

☐ TPN dependent

☐ None of the above

- Click on the comment bubble icon next to each answer field. This will open the Field Comment Log where you can enter your notes pertaining to the question/answer.

Q. Will you link this ACTION HF Registry to other databases?

- We may consider linking this registry to other registries in the future if it is possible and if it will help us answer important questions.

Q. For patients that are readmitted after discharge, what do we need to fill out?

- For patients that are re-admitted after discharge, you will need to complete some forms again. The following forms under the **Initial** and **Discharge** events will need to be completed for the new admission: Admission, Discharge, Heart Failure Status, and Medications. Please add a new instance for each of the forms by clicking the “+” sign next to the form that needs to be repeated.

Redcap ID	Enroll		Initial				Inpatient Follow-up	Discharge			
	Entry	Admission	Heart Failure Status	Medications	Cardiomems		Inpatient Follow-Up	Discharge	Heart Failure Status	Medications	Medications Discontinued
██████████	●	● +	● +	● +	●		● +	● +	● +	● +	●
██████████	●	●	● +	● +	●		●	●	●	●	●
██████████	●	●	● +	● +	●		●	●	●	●	●

Q. How often will we know if forms that have not be completed?

- In the “entry form,” there is a question to enter contact information for up to two people from your site. The designated contacts will receive a monthly ‘reminder’ email which includes the REDCap Record ID.

Q. What is the REDCap ID?

- This singular ID will link all of the ACTION HF projects together. Each patient will have their own REDCap ID. This REDCap ID is separate from the ACTION ID.

Please note the ACTION Muscular Dystrophy registry is separate and is not linked with the HF Projects.

Q. Can I designate more than one person for the follow up forms email notifications?

- Yes, in the “entry form,” there is a question to enter designated contacts for REDCap notifications. There are fields to enter a primary contact (required) and a secondary contact (optional). If you need more fields, please email ACTIONData@cchmc.org.

Q. What form status should I choose in REDCap?

- This is ultimately up to your site for how you want to track your data. We suggest the following:
 - Choose incomplete if you are not done entering the data on the form.
 - Choose unverified if you have entered the data but need to confirm it is complete.
 - Choose complete if the data has been entered fully and is ready for data analysis.

Q. What if our patient is being discharged (without VAD/Tx) and will be followed by another site?

- If the new center is an ACTION site, contact ACTION.dcc@cchmc.org.
- If the new center is not an ACTION site, please select “transferred to another site” and add a comment.