



Pediatric Heart Transplant Society

Censor Points

Updated 10/08/2018

Pre Transplant

All listed patients fall into one of four mutually exclusive categories. Once a patient encounters a censor point, no more data for events after that censor date should be reported. Additional data submission and corrections can be entered for events that occurred on or prior to the censor date.

1. Transferred Care

Pre transplant transfers should be reported on the Pre Transplant Annual Follow-up Form (Form 12) in the last question on the form. If the reason for the transfer is another censor point, such as removed from list, it should be reported as the other censor point. A patient should only fall into one censor category reported as whichever occurs first.

Once a patient encounters a censor point, no additional data for events after the censor date should be reported. Therefore, if the patient transfers back to the center that enrolled the patient in PHTS, data entry should NOT resume for that patient unless the patient is relisted (at which point they would be enrolled as a new patient).

The screenshot shows a form interface with two sections. The top section is titled 'Followed exclusively elsewhere' and has a radio button selected for 'Yes'. Below the title is a note: 'Note: If yes, no more data can be entered on this patient.' The bottom section is titled 'If yes, specify transfer date' and has a text input field with a date format 'MM/DD/YYYY' and a dropdown arrow.

2. Removal From Waiting List

Patients removed from the list should be reported on the Pre Transplant Annual Follow-up Form (Form 12) in the second to last question of the form. If the reason for removal is another censor point such as transferred to another center or death, it should be reported as the other censor point. A patient should only fall into one censor category reported as whichever occurs first.

Removal from list reasons not to be reported

The following reasons for patient being removed from list should have "no" reported for this question.

- ✗ Patient death – Form 12, question 7 should be answered as either 'no' or 'not applicable' and a death form should be submitted.
- ✗ Patient Transplanted – Form 12, question 7 should be answered as either 'no' or 'not applicable' and a transplant form should be submitted.
- ✗ Patient Transferred – Form 12, question 7 should be answered as 'no'.
The following question should be answered as 'yes'.



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Active patients that have been transplanted and relisted and are subsequently removed from the list (if the first transplant has been reported), are NOT censored at the removal from the list. Instead, Form 8s should continue to be reported until the patient meets a post-transplant censor point.

Once a patient encounters a censor point, no additional data for events after the censor date should be reported. Therefore, if the patient is removed from the list and relisted by the center that enrolled the patient in PHTS, data entry should NOT resume for that patient (at which point they would be enrolled as a new patient).

Exception to the rule:

If a patient dies within 14 days of being removed from the waiting list, this should be reported as patient death and not removed from the list.

Patient Status

7 Edit Was patient permanently removed from Transplant Waiting List since listed or last Form 12? Yes
 No
 Unknown
 Not Applicable, patient died or transplanted

Note: If patient was completely removed from the waiting list and is later relisted, the new listing should be treated as a whole new patient.

7a Edit If yes, specify date removed MM/DD/YYYY

7b Edit If yes, specify reason removed Alternate medical treatment
 Alternate surgical treatment
 Considered too well
 Contraindications/too sick
 Financial
 Neurological
 Parent/patient reluctance
 Psychosocial
 Other, specify

3. Patient Death

Pre transplant patient death should be reported by submitting a death form.

Exception to the rule:

If a patient dies within 14 days of being removed from the waiting list, this should be reported as patient death and not removed from the list.



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4. Alive and Actively Being Followed

PHTS assumes that any patient that does not have a censor event reported is considered alive and actively being followed either pre transplant or post-transplant.

Post-Transplant

All transplanted patients fall into one of three mutually exclusive categories. Once a patient encounters a censor point, no more data for events after that censor date should be reported. Additional data submission and corrections can be entered for events that occurred on or prior to the censor date.

1. Transferred Care

Post-transplant transfers should be reported on the Post-Transplant Annual Follow-up Form (Form 8). This can be reported in one of two places.

Transfer NOT at Annual Follow-up

If the patient transfers care NOT at the time of the annual follow-up, the user may select from the first question “No, patient transferred care to another center (not at time of annual follow-up)”. A subsequent question will appear asking for the transfer date and the form can be submitted.

| | | |
|----------------------------------------------------------------------------------------|-------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  7 | Was patient seen for follow-up this year | <input type="radio"/> Yes, patient was seen this year |
| | | <input type="radio"/> No, patient was not seen this year or the patient follow-up falls outside the follow-up window (+/- 90 days of the transplant anniversary) |
| | | <input checked="" type="radio"/> No, patient transferred care to another center (not at time of annual follow-up) |
|  7b | Last Date of Followup at Your Center | <input type="text"/> |

Transfer AT Annual Follow-up

If the patient transfers care at the time of the annual follow-up, the annual follow-up form should be completed with the follow-up details. Question #7 asks where the patient is being followed. If the patient is transferring care on the day of follow-up, the user should select “Patient followed exclusively at another center” and should subsequently enter the date of last follow-up (i.e. the transfer date).

| | | |
|----------------------------------------------------------------------------------------|----------------------------------------------------------------------|---------------------------------------------------------------------------------|
|  7 | Is patient currently followed at your PHTS Transplant center? | <input type="radio"/> Patient currently followed at our PHTS Transplant center |
| | | <input checked="" type="radio"/> Patient followed exclusively at another center |
|  7b | Last Date of Followup at Your Center | <input type="text"/> |



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Once this form is submitted with a transfer date reported, no additional information or events should be reported for events after the transfer date. However, if there are additional events or corrections needed for events prior to the transfer date that can be entered at any time. If the patient transfers back to the center that enrolled the patient in PHTS, data entry should NOT resume for that patient unless the patient is relisted (at which point they would be enrolled as a new patient).

2. Patient Death

Post-transplant patient death should be reported by submitting a death form.

3. Alive and Actively Being Followed

PHTS assumes that all patients that do not have a censor event reported is alive and actively being followed either pre transplant or post-transplant.