Liver Post 5 Year Transplant Recipient Follow-up (TRF) Record Field Descriptions

Transplant Recipient Follow-up (TRF) records are generated in Tiedi® at six months, one year and annually thereafter following transplantation, until either graft failure, recipient death or lost to follow-up is reported.

The TRF record is to be completed by the transplant center responsible for follow-up of the recipient at intervals of six months, one year and annually thereafter. The record is to contain only the applicable patient information since the last follow-up period, but no later than the date of death or graft failure. For example: the 6-month follow-up should contain information from the time after the TRR was completed to the 6-month transplant anniversary date; the 1-year follow-up should contain information from the day after the 6-month transplant anniversary date to the 1-year transplant anniversary date; the 2-year follow-up should contain information from the day after the 1-year transplant anniversary date to the 2-year anniversary date.

If the recipient dies or experiences a graft failure between follow-up intervals, complete an interim record containing the information pertinent to the patient **no later than the date of death or graft failure**. For example: an interim graft failure is reported with a graft failure date of March 10. The patient status date should also be March 10 and the information collected on the form should be based on patient evaluation no later than March 10.

TRF records generated before June 30, 2002 are forgiven except for the one-year, three-year, death/graft failure or most recently expected follow-up record. Amnesty records may be accessed by selecting the **Expected/Amnesty** and/or **Amnesty** option on the Search page. (For additional information, see **Searching for Patient Records – Appendix T** and **Records Generation – Appendix U**.)

If the patient is lost to follow-up, follow the steps for **Reporting Lost to Follow-up – See Appendix V**.

The TRF record must be completed within 30 days from the record generation date. See OPTN Policy for additional information. Use the search feature to locate specific policy information on Data Submission Requirements.

The TRF record must be completed within 30 days from the record generation date.

To correct information that is already displayed on an electronic record, call the UNet℠ Help Desk at 1-800-978-4334.

Recipient Information

Name: Verify the last name, first name and middle initial of the transplant recipient is correct. If the information is incorrect, corrections may be made on the recipient's TCR record.

DOB: Verify the displayed date is the recipient's date of birth. If the information is incorrect, corrections may be made on the recipient's TCR record.

SSN: Verify the recipient's social security number is correct. If the information is incorrect, contact the Help Desk at 1-800-978-4334.

Gender: Verify the recipient's gender is correct. If the information is incorrect, corrections may be made on the recipient's TCR record.

HIC: Verify the 9 to 11 character Health Insurance Claim number for the recipient indicated on the recipient's most recently updated TCR record is correct. If the recipient does not have a HIC number, you may leave this field blank.

Tx Date: The recipient's transplant date, reported in the Recipient Feedback, will display. Verify the transplant date is the date of the beginning of the first anastomosis. If the operation started in the evening and the first anastomosis began early the next morning, the transplant date is the date that the

first anastomosis began. The transplant is considered complete when the cavity is closed and the final skin stitch/staple is applied.

Previous Follow-up: The recipient's follow-up status, reported in the previous TRF record, will display. Verify the recipient's previous follow-up status is correct.

Previous Px Stat Date: The recipient's patient status date, reported in the previous TRF record, will display. Verify the recipient's previous patient status date is correct.

Transplant Discharge Date: Enter the date the recipient was released to go home, or verify that the discharge date displayed is the date the recipient was released to go home. The patient's hospital stay includes total time spent in different units of the hospital, including medical and rehab. This field is **required**.

> ***Note:*** The **Transplant Discharge Date** can only be edited on the patient's TRR, 6-month TRF and 1-year TRF. To correct this information on a follow-up that is after the 1-year TRF, access one of these three records and enter the correct date. The corrected information will automatically update on the other records.

> ***Note:*** The **Transplant Discharge Date** may be left blank on the 6-month and 1-year LIF records if the patient has not been discharged. However, this field is required on the 2-year LIF.

State of Permanent Residence: Select the name of the state of the recipient's permanent address at the time of follow-up (location of full-time residence, not follow-up center location). This field is **required**. (**List of State codes – See Appendix A**)

Permanent Zip Code: Enter the recipient's permanent zip code at the time of follow-up (location of full-time residence, not follow-up center location). This field is **required**.

Provider Information

Recipient Center: The Recipient Center information reported in Waitlist displays. Verify that the center information is the hospital where the transplant operation was performed. The Provider Number is the 6-character Medicare identification number of the hospital. This is followed by the Center Code and Center Name.

Followup Center: The follow-up center, reported in the recipient's previous validated TRF record, will display. Verify the center name, center code and provider number for the center following the patient.

Donor Information

UNOS Donor ID #: The UNOS Donor ID number, reported in the Recipient Feedback, will display. Each potential donor is assigned an identification number by OPTN/UNOS. This ID number corresponds to the date the donor information was entered into the OPTN/UNOS computer system.

Donor Type: The donor type, reported in the Recipient Feedback, will display. Verify the recipient's donor type is correct. If the information is incorrect, contact the Help Desk at 1-800-978-4334.

Deceased indicates the donor was not living at the time of donation.
Living indicates the donor was living at the time of donation.

Patient Status (At Time of Follow-up)

Date: Last Seen, Retransplanted or Death Enter the date the patient was last seen, the date of death, the date of graft failure, or retransplant for this recipient, using the standard 8-digit numeric format of MM/DD/YYYY. The follow-up records (6 month, 1 Year, 2 Year, etc.) are to be completed within 30 days of the 6 month and yearly anniversaries of the transplant date. If the recipient died or the graft failed, and you have not completed an interim follow-up indicating these events, the 6 month and annual follow-ups should be completed indicating one of those two events. This field is **required**.

Patient Status: If the recipient is living at the time of follow-up, select **Living**. If the recipient died during this follow-up period, select **Dead**. If the recipient received another kidney from a different donor during the follow-up period, select **Retransplanted**. If **Dead** is selected, indicate the cause of death. This field is **required**.

Living
Dead
Retransplanted

Primary Cause of Death: If the Patient Status is **Dead**, select the patient's cause of death. If an **Other** code is selected, enter the other cause of death in the space provided. (**List of Primary Cause of Death codes – See Appendix K**)

Functional Status: (Complete for recipients younger than 18 years of age at transplant and younger than 26 years of age at follow-up.) Select the choice that best describes the recipient's functional status at the time of follow-up. This field is **required**.

100% - Fully active, normal
90% - Minor restrictions in physically strenuous activity
80% - Active, but tires more quickly
70% - Both greater restriction of and less time spent in play activity
60% - Up and around, but minimal active play; keeps busy with quieter activities
50% - Can dress but lies around much of day; no active play; can take part in quiet play/activities
40% - Mostly in bed; participates in quiet activities
30% - In bed; needs assistance even for quiet play
20% - Often sleeping; play entirely limited to very passive activities
10% - No play; does not get out of bed
Not Applicable (patient < 1 year old)
Unknown

Note: This evaluation should be in comparison to the person's normal function, indicating how the patient's disease has affected their normal function.

Cognitive Development: (Complete for recipients younger than 18 years of age at transplant and younger than 26 years of age at follow-up.) Select the choice that best describes the recipient's cognitive development at the time of follow-up.

Definite Cognitive Delay/Impairment (verified by IQ score <70 or unambiguous behavioral observation)

Probable Cognitive Delay/Impairment (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence)

Questionable Cognitive Delay/Impairment (not judged to be more likely than not, but with some indication of cognitive delay/impairment such as expressive/receptive language and/or learning difficulties)

No Cognitive Delay/Impairment (no obvious indicators of cognitive delay/impairment)

Not Assessed

Motor Development: (Complete for recipients younger than 18 years of age at transplant and younger than 26 years of age at follow-up.) Select the choice that best describes the recipient's motor development at the time of follow-up.

Definite Motor Delay/Impairment (verified by physical exam or unambiguous behavioral observation)

Probable Motor Delay/Impairment (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence)

Questionable Motor Delay/Impairment (not judged to be more likely than not, but with some indication of motor delay/impairment)

No Motor Delay/Impairment (no obvious indicators of motor delay/impairment)

Not Assessed

Clinical Information

Date of Measurement: (Complete for recipients younger than 18 years of age at transplant and younger than 26 years of age at follow-up.) Enter the date, using the 8-digit format of MM/DD/YYYY, the recipient's height and weight were measured. This field is **required**.

Height: (Complete for recipients younger than 18 years of age at transplant and younger than 26 years of age at follow-up.) Enter the height of the recipient at the time of follow-up in the appropriate space, in feet and inches or centimeters. This field is **required**. If the recipient's height is unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).UNet will generate and display calculated percentiles based on the 2000 CDC growth charts.

Weight: (Complete for recipients younger than 18 years of age at transplant and younger than 26 years of age at follow-up.) Enter the weight of the recipient at the time of follow-up in the appropriate space, in pounds or kilograms. This field is **required**. If the recipient's weight is unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). UNet will generate and display calculated percentiles based on the 2000 CDC growth charts.

BMI (Body Mass Index)**:** For candidates less than 20 years of age during the follow-up period, UNet will generate and display calculated percentiles based on the 2000 CDC growth charts.

Percentiles are the most commonly used clinical indicator to assess the size and growth patterns of individual children in the United States. Percentiles rank the position of an individual by indicating what percent of the reference population the individual would equal or exceed (i.e. on the weight-for-age growth charts, a 5 year-old girl whose weight is at the 25th percentile, weighs the same or more than 25 percent of the reference population of 5-year-old girls, and weighs less than 75 percent of the 5-year-old girls in the reference population). For additional information about CDC growth charts, see http://www.cdc.gov/.

Note: Users who check the BMI percentiles against the CDC calculator may notice a discrepancy that is caused by the CDC calculator using 1 decimal place for height and weight and UNet^{sm} using 4 decimal places for weight and 2 for height.

Graft Status: If the graft is functioning at the time of follow-up, select **Functioning**. If the graft is not functioning at the time of follow-up, select **Failed.**

Note: If death is indicated for the recipient, and the death was a result of some other factor unrelated to graft failure, select **Functioning**.

If **Failed** is selected, complete the following fields:

Date of Failure: Enter the date of graft failure using the standard 8-digit numeric format of MM/DD/YYYY.

Causes of graft failure: Select the causes of graft failure. If **Other, Specify** is selected, enter the cause of failure in the space provided.

Primary Non-Function (PNF)

Hepatic Artery Thrombosis (HAT)

Other Vascular Thrombosis

DeNovo Hepatitis

Diffuse Cholangiopathyse
Recurrent Hepatitis
Recurrent Disease
Acute Rejection
Chronic Rejection
Infection
Other, Specify

If **Vascular Thrombosis** is selected for pediatric recipients, complete the following information:

Hepatic arterial thrombosis: If the recipient had a hepatic arterial thrombosis, select **Yes**. If not, select **No**. If unknown, select **Unknown**.

Hepatic outflow obstruction: If the recipient had hepatic outflow obstruction, select **Yes**. If not, select **No**. If unknown, select **Unknown**.

Portal vein thrombosis: If the recipient had portal vein thrombosis, select **Yes**. If not, select **No**. If unknown, select **Unknown**.

New diabetes onset during the last follow-up to the current follow-up: If the recipient developed diabetes during the follow-up period, select **Yes**. If new onset of diabetes was already reported on last follow-up, do not report it again on current follow-up. If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, indicate whether the recipient was dependent on insulin.

If yes, insulin dependent: If the recipient is insulin dependent, select **Yes**. If not, select **No**. If unknown, select **UNK**.

Coronary Artery Disease Since Last Follow-up: (Complete for recipients less than 18 years of age at transplant and less than 26 years of age at follow-up.) If the recipient has experienced new signs and symptoms of coronary artery disease at the time of follow-up, select **Yes**. If not, select **No**. If unknown, select **Unk**.

Postransplant Malignancy: If the recipient has been diagnosed with any malignant cancer since the last follow-up, select **Yes**. If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, at least one of the fields listed below must be completed. A Post Transplant Malignancy record will generate when one or more of the fields listed below is selected. For additional information, see **Post Transplant Malignancy Record Fields**.

Donor Related: If the malignancy is donor related, select **Yes**. If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, the Donor Related section will be displayed on the Post Transplant Malignancy record. For additional information, see **Post Transplant Malignancy Record Fields - Donor Related**.

Recurrence of Pre-Tx tumor: If a pre-transplant tumor has recurred, select **Yes**. If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, the Recurrence of Pretransplant Malignancy section will be displayed on the Post Transplant Malignancy record. For additional information, see **Post Transplant Malignancy Record Fields - Recurrence of Pretransplant Malignancy**.

De Novo Solid Tumor: If the cancer was a De Novo solid tumor, select **Yes.** If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, the Post Transplant De Novo Solid Tumor section will be displayed on the Post Transplant Malignancy record. For additional information, see **Post Transplant Malignancy Record Fields - Post Transplant De Novo Solid Tumor**.

De Novo Lymphoproliferative disease and Lymphoma: If the cancer was post transplant lymphoproliferative disease or lymphoma, select **Yes**. If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, the Post Tx Lymphoproliferative Disease and Lymphoma section will be displayed on the Post Transplant Malignancy record. For additional information, see **Post Transplant Malignancy Record Fields - Post Tx Lymphoproliferative Disease and Lymphoma**.

Note: Please report each type of malignancy only once in the follow-up process.

Note: When a patient has a tumor during one follow up period and the tumor continues into the next follow-up period without going away, the tumor should only be reported on that first follow-up record and not reported on the next follow-up record. The tumor should be reported on subsequent follow-up records ONLY if the tumor goes away and then returns in the next follow-up period.