Intestine Transplant Recipient Follow Up Post 5 Year

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. Forms are generated by the age at transplant, not the age at listing. Pediatric follow-up records will continue to generate through the recipient's 25th birthday. The system will automatically update the next follow-up record to Adult as of the recipient's 26th birthday.

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. It is not to contain information pertaining solely to the previous or next follow-up period. 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.

If the patient is lost to follow-up, follow the steps for Reporting Lost to Follow-up.

The TRF record must be completed within 90 days from the record generation date. See OPTN Policies for additional information. Use the search feature to locate specific policy information on Data Submission Requirements.

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.

Birth Sex: Verify recipient's sex (Male or Female), based on biologic and physiologic traits at birth. If sex at birth is unknown, report sex at time of registration as reported by recipient or documented in medical record. The intent of this data collection field is to capture physiologic characteristics that may have an impact on recipient size matching or graft outcome. 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 that the displayed transplant date is correct. The transplant date is determined by the start of the organ anastomosis during transplant or the start of the islet infusion. Organ transplants include solid organ transplants and islet infusions. An organ transplant procedure is complete when any of the following occurs:

The chest or abdominal cavity is closed and the final skin stitch or staple is applied.

The transplant recipient leaves the operating room, even if the chest or abdominal cavity cannot be closed.

The islet infusion is complete.

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.

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)

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.

Follow-up 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

Date: Last Seen, Retransplanted or Death: Enter the date the patient was last seen, the date of death, or the date of 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**. Follow-up forms will no longer be generated for this patient. If **Dead** is selected, indicate the cause of death. If the recipient received another intestine from a different donor during the follow-up period, select **Retransplanted**. If the recipient was not seen during this follow-up period, select **Not Seen**; however, an annual follow-up form will be generated for this patient next year. This field is **required**.

Living
Dead
Retransplanted
Not Seen

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)

Functional Status: (Complete for recipients younger than 18 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 follow-up.) Select the choice that best describes the recipient's cognitive development at the time of follow-up. This field is **required**.

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 follow-up.) Select the choice that best describes the recipient's motor development at the time of follow-up. This field is **required**.

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

Height 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 was measured. This field is **required**.

Height: (Complete for recipients younger than 18 years of age 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. If the recipient's height is unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). (List of Status codes) UNet will generate and display calculated percentiles based on the 2000 CDC growth charts. This field is **required**.

Weight 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 weight was measured. This field is **required**.

Weight: (Complete for recipients younger than 18 years of age at 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. If the recipient's weight is unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). (List of Status codes) UNet will generate and display calculated percentiles based on the 2000 CDC growth charts. This field is **required**.

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

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 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**. This field is **required**.

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**, provide the following information:

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

Primary Cause of Failure: Select the cause of graft failure. If **Other Specify** is selected, enter the cause of graft failure in the space provided. (Adult Primary Cause of Failures codes) (Pediatric Primary Cause of Failure codes)

Recurrent Tumor
Acute Rejection
Chronic Rejection
Technical Problems
Infection
Lymphoproliferative Disease
Patient Noncompliance
Graft Versus. Host Disease
Ischemia/NEC Like Syndrome (Necrotizing Enterocolitis)
Other Specify

Most Recent Serum Creatinine: Enter the most recent lab value for the serum creatinine value in mg/dl taken closest to the time of follow-up. If the value is not available, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**) (List of Status codes). This field is **required**.

Post Transplant 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. This field is **required**.

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: 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.

Public Burden Statement: The private, non-profit Organ Procurement and Transplantation Network (OPTN) collects this information in order to perform the following OPTN functions: to assess whether applicants meet OPTN Bylaw requirements for membership in the OPTN; and to monitor compliance of member organizations with OPTN Obligations. An agency may not conduct or sponsor, and a person

is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this information collection is 0915-0157 and it is valid until XX/XX/202X. This information collection is required to obtain or retain a benefit per 42 CFR §121.11(b)(2). All data collected will be subject to Privacy Act protection (Privacy Act System of Records #09-15-0055). Data collected by the private non-profit OPTN also are well protected by a number of the Contractor's security features. The Contractor's security system meets or exceeds the requirements as prescribed by OMB Circular A-130, Appendix III, Security of Federal Automated Information Systems, and the Departments Automated Information Systems Security Program Handbook. The public reporting burden for this collection of information is estimated to average 0.27 hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Information Collection Clearance Officer, 5600 Fishers Lane, Room 14N39, Rockville, Maryland, 20857 or paperwork@hrsa.gov.