# Kidney-Pancreas Transplant Recipient Follow-up (TRF) 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. 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 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.

**Gender:** 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 beginning of organ anastomosis. For a multi-organ transplant procedure, the transplant date for each organ is determined by the transplant date of the first organ transplanted.

**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.

> *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.

**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.

**Physician Name:** Enter the name of the physician who is following the patient. If the patient is being seen by a nurse practitioner or physician's assistant, enter the name of the practitioner providing care (e.g. physician, nurse practitioner, physician's assistant).

**NPI #:** Enter the 10-character CMS (Center for Medicare and Medicaid Services, formerly HCFA) assigned National Provider Identifier of the transplant physician or practitioner providing care (e.g. physician, nurse practitioner, physician's assistant). Your hospital billing office may be able to obtain this number for you.

**Follow-up Care Provided By:** Indicate where the follow-up care was provided. If **Other Specify** is selected, specify the provider in the space provided. (List of Provider Type codes)

> **Transplant Center**
> **Non Transplant Center Specialty Physician**
> **Primary Care Physician**
> **Other Specify**

## 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.

**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 kidney 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**. *Note:* When reporting an interim death for a KP transplant recipient, it is possible to report that one organ was functioning and the other had failed. If you need to report this scenario, please contact UNOS Customer Service at 1-800-978-4334.

    **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](#))

    *Note:* If the **Patient Status** is **Retransplanted** for the kidney(s), then the following fields are not applicable:

        **Kidney Graft Status**
        **Most Recent Serum Creatinine**
        **Kidney Date of Failure**
        **Kidney Primary Cause of Graft Failure**
        **Contributory causes of graft failure**
        **Dialysis Since Last Follow-Up**
        **Did patient have any kidney acute rejection episodes during the follow-up period**

    *Note:* If the **Patient Status** is **Retransplanted** for the pancreas, then the following fields are not applicable:

        **Pancreas Graft Status**
        **Method of Blood Sugar Control**
        **Pancreas Date of Failure**
        **Pancreas Graft Removed**
        **Pancreas Primary Causes of Graft Failure**
        **Contributory Causes of Graft Failure**
        **Conv. from Bladder to Enteric Drain Performed**
        **Serum Amylase**
        **Pancreas Transplant Complications (Not leading to graft failure)**
        **Did patient have any pancreas acute rejection episodes during the follow-up period**

**Has the patient been hospitalized since the last patient status date:** If the recipient has been hospitalized since the last patient status report, regardless of patient status (living, dead, or retransplanted), select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

*Note:* Hospitalizations should ONLY include inpatient visits.

**Functional Status:** Select the choice that best describes the recipient's functional status at the time of follow-up. This field is **required**.

*Note:* The Karnofsky Index will display for adults aged 18 and older.

100% - Normal, no complaints, no evidence of disease
90% - Able to carry on normal activity: minor symptoms of disease
80% - Normal activity with effort: some symptoms of disease
70% - Cares for self: unable to carry on normal activity or active work
60% - Requires occasional assistance but is able to care for needs
50% - Requires considerable assistance and frequent medical care
40% - Disabled: requires special care and assistance
30% - Severely disabled: hospitalization is indicated, death not imminent
20% - Very sick, hospitalization necessary: active treatment necessary
10% - Moribund, fatal processes progressing rapidly
Unknown

*Note:* The Lansky Score will display for pediatrics aged less than 18.

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. (List of Cognitive Development codes)

**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. (List of Motor Development codes)

**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**

**Working for income:** (Complete for recipients 18 years of age or older.) If the recipient was working for income at the time of follow-up, select **Yes**. If not, select **No**. If reporting the recipient's death, indicate if the recipient was working for income just prior to death.

**If No, Not Working Due To:** If **No** is selected, indicate the reason why the recipient was not working. (This field is optional for **adult** recipients only.) (List of Not Work Reason codes)

**Disability -** A physical or mental impairment that interferes with or prevents a recipient from working (e.g. arthritis, mental retardation, cerebral palsy, etc).

**Demands of Treatment -** An urgent medical treatment that prevents a recipient from working (e.g. Dialysis).

**Insurance Conflict -** Any differences between a recipient and insurance company that prevents them from working.

**Inability to Find Work -** The lack of one's ability to find work (e.g. lack of transportation, work experience, over qualification, unavailable work, etc.).

**Patient Choice - Homemaker -** A recipient who chooses to manage their own household, instead of performing work for pay.

**Patient Choice - Student Full Time/Part Time -** A recipient who is enrolled and/or participating in college.

**Patient Choice - Retired -** A recipient who no longer has an active working life such as an occupation, business or office job.

**Patient Choice - Other -** Any reason not listed above that would prevent a recipient from working.

**Not Applicable - Hospitalized -** Select only if the patient's Medical Condition indicates they are in the hospital.

**Unknown**

**If Yes:** If **Yes** is selected, indicate the recipient's working status. (This field is optional for **adult** recipients only.) (List of Working codes)

**Working Full Time**
**Working Part Time due to Demands of Treatment**
**Working Part Time due to Disability**
**Working Part Time due to Insurance Conflict**
**Working Part Time due to Inability to Find Full Time Work**
**Working Part Time due to Patient Choice**
**Working Part Time Reason Unknown**
**Working, Part Time vs. Full Time Unknown**

**Academic Progress:** (This field is **required** for recipients less than 18 years of age.) Select the choice that best describes the recipient's academic progress at the time of follow-up. If reporting the recipient's death, select the choice that best describes the recipient's academic progress just prior to death. If the

recipient too young for school or has graduated from high school, select **Not Applicable, too young for school/High School graduate or GED**.

> **Within One Grade Level of Peers**
> **Delayed Grade Level**
> **Special Education**
> **Not Applicable, too young for school/High School graduate or GED**
> **Status Unknown**

**Academic Activity Level:** (This field is **required** for recipients less than 18 years of age.) Select the choice that best describes the recipient's academic activity level at the time of follow-up. If reporting the recipient's death, select the choice that best describes the recipient's academic level just prior to death. If the recipient is too young for school or has graduated from high school, select **Not Applicable, too young for school/High School graduate or GED**.

> **Full academic load**
> **Reduced academic load**
> **Unable to participate in academics due to disease or condition**
> **Not Applicable, too young for school/High School graduate or GED**
> **Status Unknown**

**Primary Insurance at Follow-up:** Select the recipient's source of primary payment (largest contributor) during the follow-up period. (List of Primary Insurance codes)

> **Private insurance** refers to funds from agencies such as Blue Cross/Blue Shield, etc.  It also refers to any worker's compensation that is covered by a private insurer.

> **Public insurance - Medicaid** refers to state Medicaid funds.

> **Public insurance - Medicare FFS** (Fee-for-Service) refers to funds, from the government in which doctors and other health care providers are paid for each service provided to a recipient. For additional information about Medicare, see http://www.medicare.gov/.

> **Public insurance - Medicare & Choice (also known as Medicare Managed Care)** refers to funds from the government in which doctors and other health care providers are paid for each service provided to a recipient, along with additional benefits such as coordination of care or reducing-out-of-pocket expenses. Sometimes a recipient may receive additional benefits such as prescription drugs. For additional information about Medicare, see http://www.medicare.gov/.

> **Public insurance - CHIP (Children's Health Insurance Program)**

> **Public insurance - Department of VA** refers to funds from the Veterans Administration.

> **Public insurance - Other government**

> **Self** indicates that the cost of follow-up will be paid for by the recipient.

> **Donation** indicates that a company, institution, or individual(s) donated funds to pay for the follow-up period and care of the recipient.

> **Free Care** indicates that the transplant hospital will not charge recipient for the costs of the follow-up period.

> **Foreign Government** refers to funds provided by foreign government (Primary only). Specify foreign country in the space provided. (List of Foreign Country codes)

> **Unknown**

## 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:** 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](#)) For recipients 18 years old or younger at the time of follow-up, UNet will generate and display calculated percentiles based on the 2000 CDC growth charts. This field is optional for **adult** recipients only.

**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:** 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](#)) For recipients 18 years old or younger at the time of follow-up, 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 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/](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.

**Bone Disease (check all that apply):** (Complete for recipients younger than 18 years of age at transplant and younger than 26 years of age at follow-up.)

> **Fracture in the past year:** If the recipient had any fractures in the past year, select **Yes**. If not, select **No**. If unknown, select **UNK**.

> > If **Yes** is selected, specify the location and number of fractures

> > > **Spine-compression, #**
> > > **Extremity, #**
> > > **Other, #**

> **AVN (avascular necrosis):**If the recipient has AVN at the time of listing, select **Yes**. If not, select **No**. If unknown, select **UNK**.

**Kidney Graft Status:** If the kidney graft is functioning at the time of follow-up, select **Functioning**. If the kidney graft is not functioning at the time of follow-up, select **Failed**. If the **Patient Status** is **Retransplanted** for the kidney(s), this field is not applicable.

> *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 **Functioning**, **Most Recent Serum Creatinine:** Enter the most recent serum creatinine, in mg/dl, available if the recipient's kidney graft was functioning at the time of follow-up. If unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). ([List of Status codes](#)) If the **Patient Status** is **Retransplanted** for the kidney(s), this field is not applicable.

> If **Failed**, provide the following information:

**Kidney Date of Failure:** Enter the date using the standard 8-digit numeric format of MM/DD/YYYY.  If the **Patient Status** is **Retransplanted** for the kidney(s), this field is not applicable.

**Kidney Primary Cause of Graft Failure:** Select the cause of graft failure. If **Other, Specify** is selected, enter the cause of failure in the space provided. If the **Patient Status** is **Retransplanted** for the kidney(s), this field is not applicable. (List of Kidney Graft Failure codes)

> **Acute Rejection**
> **Graft Thrombosis**
> **Infection**
> **Urological Complications**
> **Recurrent Disease**
> **Chronic Rejection**
> **BK (Polyoma) Virus**
> **Primary Non-Function (Graft Never Functioned Post-Transplant)**
> **Other, Specify**

*Note:* If the kidney/pancreas recipient experiences a graft failure of both the kidney and pancreas between follow-up intervals, complete an Interim record containing the information pertinent to death or graft failure. However, if the recipient experiences graft failure of only one organ, then the graft failure must be reported on the next expected KPF record. It may also be reported on the last completed record for the failed organ if it occurred within 2 months of the record completion date.

**Dialysis Since Last Follow-up:** If the recipient has received dialysis during the follow-up period, select **Yes**. If not, select **No**. If unknown, select **Unknown**. If a **Yes** choice was selected, enter the date the dialysis resumed and the dialysis provider. If the **Patient Status** is **Retransplanted** for the kidney(s), this field is not applicable. (List of Dialysis codes)

> **No**
> **Yes, returned to chronic maintenance dialysis (ESRD)**
> **Yes, returned to (or continued on) temporary dialysis**

> **Date Maintenance Dialysis Resumed:** If the recipient returned to dialysis, enter the date using the standard 8-digit numeric format of MM/DD/YYYY.

**Pancreas Graft Status:** Select the status that best describes the pancreas graft status. If the **Patient Status** is **Retransplanted** for the pancreas, this field is not applicable.

*Note: If death is indicated for the recipient, report graft status up until the instance of death.*

**Functioning:** The graft has sufficient function so that the recipient is **NOT** receiving a level of insulin for blood sugar control that constitutes a failed graft (0.5 kg of insulin a day for 90 consecutive days).

**Failed:** The graft has failed when **ANY** of the following occurs:

- A recipient's transplanted pancreas is removed

- A recipient re-registers for a pancreas

- A recipient registers for an islet transplant after receiving a pancreas transplant

- A recipient's insulin use is greater than or equal to 0.5 units/kg/day for a consecutive 90 days

- A recipient dies

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

**Pancreas Date of Failure:** Enter the date of failure using the standard 8-digit numeric format of MM/DD/YYYY.  If the **Patient Status** is **Retransplanted** for the pancreas, this field is not applicable.

*Note:* The date of failure and the date insulin was resumed should be the same, unless the patient has a previous partial graft function reported.

**Pancreas Graft Removed:** Select **Yes** if the pancreas graft has totally failed, the recipient is completely dependent on insulin for blood glucose control, and the pancreas graft was removed. If not, select **No**. If unknown, select **Unknown**. If the **Patient Status** is **Retransplanted** for the pancreas, this field is not applicable. This field is optional.

**Date Pancreas Graft Removed:** If **Yes** is selected, enter the date the pancreas graft was removed using the standard 8-digit numeric format MM/DD/YYYY. This field is optional.

**Pancreas Primary Causes of Graft Failure:** Select the primary cause of graft failure. If **Other Specify** is selected, enter the cause of graft failure in the space provided. If the **Patient Status** is **Retransplanted** for the pancreas, this field is not applicable. (List of Pancreas Graft Failure codes)

**Pancreas Graft/Vascular Thrombosis**
**Pancreas Infection**
**Pancreas Bleeding**
**Anastomotic Leak**
**Pancreas Rejection: Acute**
**Pancreas Chronic Rejection**
**Biopsy Proven Isletitis**
**Pancreatitis**
**Patient Noncompliance**
**Other Specify**

*Note:* If the kidney/pancreas recipient experiences a graft failure of both the kidney and pancreas between follow-up intervals, complete an Interim record containing the information pertinent to death or graft failure. However, if the recipient experiences graft failure of only one organ, then the graft failure must be reported on the next expected KPF record. It may also be reported on the last completed record for the failed organ if it occurred within 2 months of the record completion date.

**Patient using either oral medication or diet for blood sugar control:** Answer whether the patient is using diet or medication for blood sugar control, **not including insulin**. *This includes injectable, non-insulin medications.* Select **Yes**, **No**, or **UNK** to indicate whether the patient is using any method of blood sugar control. This field is **required**.

*Note:* The intent of this field is to collect data on prescribed blood sugar maintenance. Extraneous methods sought out by a recipient outside of the prescribed regimen should not be taken into account when reporting on known methods of blood sugar control.  For example, if it is known that a recipient is not on oral medication for blood sugar control, but it is unknown whether a recipient is using a diet not prescribed by the center (extraneous to the treatment plan), the user should enter No.

If **Yes**, complete the following fields:

**Patient on oral medication to control blood sugar?:** Select **Yes**, **No**, or **UNK** to indicate whether the patient is on oral medication to control blood sugar. This field is **required**.

**Date of medications resumed:** Enter the date medications resumed using the standard 8-digit numeric format of MM/DD/YYYY. Date must be greater than or equal to transplant date. If

unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). This field is **required**.

**Patient using diet to control blood sugar:** Select **Yes**, **No**, or **UNK** to indicate whether the patient is using diet to control blood sugar. This field is **required**.

**Patient on insulin?** Select **Yes**, **No**, or **UNK** to indicate whether the patient is currently on insulin as of the patient status date. This field is **required**.

If **Yes**, complete the following fields:

**Date insulin resumed:** Enter the date insulin resumed using the standard 8-digit numeric format of MM/DD/YYYY. Date must be after date of birth and before and/or equal to today's date. If unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). This field is **required**.

**Average total insulin dosage per day:** Enter the average daily total insulin dosage units (units/kg/day) in the space provided. Average daily insulin dose should be a total including all insulin administered in any form per day (short term, long term, by pump, subcutaneous). The insulin dosage units must be between 1 and 1000. If the value is unavailable, select the appropriate status from the ST field (**N/A**, **Not Done**, **Missing**, **Unknown**). This field is **required**.

**Insulin duration of use:** Enter the insulin duration of use (days) for the current dosage in the space provided. If unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). This field is **required**.

**C-peptide value:** Enter the c-peptide value in ng/mL. The value must be between 0.00 and 99.90. If unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). This value is required if graft status is functioning.

**HbA1c:** Enter the HbA1c percentage in the space provided. The value must be between 0.0 and 99.9. If unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). This value is required if graft status is functioning.

**Conv. From Bladder to Enteric Drain Performed:** If the pancreas graft duct has been changed from bladder to enteric during this follow-up period, select **Yes**. If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, indicate when the conversion occurred. On the recipient's TRR, if **Enteric w/Roux-En-Y** or **Enteric w/o Roux-En-Y** was selected for Duct Management, this question does not apply for this recipient and you must select **N/A**. If the **Patient Status** is **Retransplanted** for the pancreas, this field is not applicable.

**Enteric Drain Date:** If **Yes** is selected, enter the date of the conversion during this follow-up period using the standard 8-digit numeric format of MM/DD/YYYY.

**Pancreas Transplant Complications (Not leading to graft failure):** For each of the complications listed, indicate if the complication occurred during this follow-up period. Do not select **Yes** if the complication contributed to failure of the pancreas graft. If the **Patient Status** is **Retransplanted** for the pancreas, this field is not applicable.

**Pancreatitis:** If the recipient was diagnosed as having pancreatitis, select **Yes**. If not, select **No**. If unknown, select **UNK**.

**Anastomotic Leak:** If the recipient exhibited signs and symptoms of an anastomotic leak during this follow-up period, select **Yes**. If not, select **No**. If unknown, select **UNK**.

**Abscess or Local Infection:** If the recipient exhibited graft-related signs and symptoms of abscess or local infection during this follow-up period, select **Yes**. If not, select **No**. If unknown, select **UNK**.

**Other, Specify:** If a complication other than those listed occurred during this follow-up period, select **Other, Specify** and enter the complication in the space provided.

**Did patient have any kidney acute rejection episodes during the follow-up period:** If the recipient experienced at least one episode during this follow-up period, select **Yes**. If not, select **No**. If unknown, select **Unknown**. If the **Patient Status** is **Retransplanted** for the kidney(s), this field is not applicable. (List of Any Acute Rejection Episodes codes)

**Yes, at least one episode treated with anti-rejection agent**
**Yes, none was treated with additional anti-rejection agent**
**No**
**Unknown**

**Did patient have any pancreas acute rejection episodes during the follow-up period**: If the recipient experienced at least one episode during this follow-up period, select **Yes**. If not, select **No**. If unknown, select **Unknown**. If the **Patient Status** is **Retransplanted** for the pancreas, this field is not applicable. (List of Any Acute Rejection Episodes codes)

**Yes, at least one episode treated with anti-rejection agent**
**Yes, none was treated with additional anti-rejection agent**
**No**
**Unknown**

**Viral Detection:**

*Note:* The CMV IgG and CMV IgM fields are required on 1-year and 2-year TRF forms.

**CMV IgG:** Select the results from the list. This field is required.

**Positive**
**Negative**
**Not Done**
**UNK/Cannot Disclose**

**CMV IgM:** Select the results from the list. This field is **required**.

**Positive**
**Negative**
**Not Done**
**UNK/Cannot Disclose**

*Note:* The following fields will be required on 6-month and 1-year TRF forms if the recipient received an organ from a donor that was classified as "increased risk" on the DDR.

**HIV Serology:** Select the results from the list.

**Positive**
**Negative**
**UKN/Cannot Disclose**
**Not Done**

**HIV NAT (Nucleic Acid Testing):** PCR or NAT testing can be used to submit response. Select the results from the drop-down list.

**Positive**
**Negative**
**UKN/Cannot Disclose**
**Not Done**

**HbsAg:** Select the results from the list.

**Positive**
**Negative**

**UKN/Cannot Disclose**
**Note Done**

**HBV DNA:** PCR or NAT testing can be used to submit response. Select the results from the drop-down list.

**Positive**
**Negative**
**UKN/Cannot Disclose**
**Not Done**

**HBV Core Antibody:** Select the results from the list.

**Positive**
**Negative**
**UKN/Cannot Disclose**
**Not Done**

**HCV Serology:** Select the results from the list.

**Positive**
**Negative**
**UKN/Cannot Disclose**
**Not Done**

**HCV NAT:** PCR or NAT testing can be used to submit response. Select the results from the list.

**Positive**
**Negative**
**UKN/Cannot Disclose**
**Not Done**

**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.

**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.

**Bone Disease (check all that apply):** (Complete for recipients less than 18 years of age.)

**Fracture in the past year (or since last follow-up):** If the recipient had any fractures in the past year, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

If **Yes** is selected, specify the location and number of fractures ( If **Yes** is selected, this field is required.)

**Spine-compression fracture:**      **#of fractures:**
**Extremity:**                  **# of fractures:**
**Other:**                    **# of fractures:**

**AVN (avascular necrosis):** If the recipient has AVN at the time of transplant, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required** for recipients less than 18 years of age.

---

## Immunosuppressive Information

**Previous Validated Maintenance Follow-up Medications:** The follow-up Immunosuppression medication(s) indicated in the patient's most recently validated Transplant Recipient Registration (TRR) or Transplant Recipient Follow-up (TRF) record will be listed.

*Note:* If a drug cannot be indicated as **Maintenance** in the Transplant Recipient Registration (TRR), then it cannot be indicated as **Current Maintenance** or **Previous Maintenance** in the TRF. If the drug cannot be indicated as **Anti-rejection** in the TRR, then it cannot be indicated as **Anti-rejection** in the TRF.

**Were any medications given during the follow-up period for maintenance:** (List of Changes to Maintenance Medications codes)

If there were immunosuppressive medications during this follow-up period, select **Yes, same as validated TRR form.** The drugs on the previously validated TRR will pre-populate.

If there have been changes in medications during this follow-up period, select **Yes, but different than validated TRR form**. Then select the appropriate Immunosuppressive Medications by placing a checkmark in the **Current Maint** or **AR** column.

If no medications were given during this follow-up period, select **None given**.

*Note:* If any medications were given during the 6-month follow-up period for maintenance, immunosuppression medications from the patient's validated TRR will be listed.

---

## Definitions of Immunosuppressive Follow-up Medications

For each of the immunosuppressant medications listed, check Previous Maintenance (Prev Maint), Current Maintenance (Curr Maint) or Anti-rejection (AR) to indicate all medications that were prescribed for the recipient during this follow-up period, and for what reason. If a medication was not given, leave the associated box(es) blank.

**Previous Maintenance (Prev Maint)** includes all immunosuppressive medications given during the report period, which covers the period from the last clinic visit to the current clinic visit, with the intention to maintain them long-term (example: prednisone, cyclosporine, tacrolimus, mycophenolate mofetil, azathioprine, or Rapamune). This does not include any immunosuppressive medications given to treat rejection episodes.

**Current Maintenance (Curr Maint)** includes all immunosuppressive medications given at the time of the current clinic visit to begin in the next report period, with the intention to maintain them long-term

(example: prednisone, cyclosporine, tacrolimus, mycophenolate mofetil, azathioprine, or Rapamune). This does not include any immunosuppressive medications given to treat rejection episodes.

**Anti-rejection (AR)** immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode since the last clinic visit (example: methylprednisolone or Thymoglobulin). When switching maintenance drugs (example: from tacrolimus to cyclosporine; or from mycophenolate mofetil to azathioprine) because of rejection, the drugs should not be listed under AR immunosuppression, but should be listed under maintenance immunosuppression. ***Note:*** The Anti-rejection field refers to any anti-rejection medications since the last clinic visit, not just at the time of the current clinic visit.

If an immunosuppressive medication other than those listed is being administered (e.g., new monoclonal antibodies), select Previous Maint, or Current Maint, or AR next to Other Immunosuppressive Medication field, and enter the full name of the medication in the space provided. ***Note:*** Do not list non-immunosuppressive medications.

## Drug used for induction, acute rejection, or maintenance

Steroids (prednisone, methylprednisolone, Solumedrol, Medrol)

## Drugs used for induction or acute rejection

Atgam

Campath (alemtuzumab)

Cytoxan (cyclophosphamide)

Methotrexate (Folex PFS, Mexate-AQ, Rheumatrex)

Rituxan (rituximab)

Simulect (basiliximab)

Thymoglobulin

## Drugs primarily used for maintenance

**Cyclosporine, select from the following:**

- Gengraf
- Neoral
- Sandimmune
- Generic cyclosporine
- Imuran (azathioprine, AZA)
- Leflunomide (LFL)

**Mycophenolic acid, select from the following:**

- CellCept (MMF)
- Generic MMF (generic CellCept)
- Myfortic (mycophenolic acid)

- Generic Myfortic (generic mycophenolic acid)

**mTOR inhibitors, select from the following:**

- Rapamune (sirolimus)
- Generic sirolimus
- Zortress (everolimus)
- Nulojix (belatacept)

**Tacrolimus, select from the following:**

- Astagraf XL (extended release tacrolimus)
- Envarsus XR (tacrolimus XR)
- Prograf (tacrolimus)
- Generic tacrolimus (generic Prograf)
-

## Other drugs

Other immunosuppressive medication, specify: