Kidney Transplant Recipient Registration (TRR) Record Field Descriptions

The Transplant Recipient Registration (TRR) records are generated after a transplant event is reported through the recipient feedback process in Waitlist℠. A TRR will also be generated in the case of a living donor transplant, where a recipient was added through the donor feedback process in Tiedi®. The Transplant Recipient Registration (TRR) record is completed by the transplant center performing the transplant. The registration and hospital discharge follow-up information is combined in this record.

Complete the TRR at hospital discharge or six weeks post-transplant, whichever comes first. If the recipient is still hospitalized at six weeks post-transplant, provide the most recent information available regarding the recipient's progress.

View OPTN/UNOS Policy on Data Submission Requirements for additional information.

To correct information that is already displayed on an electronic record, call 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: Verify the displayed 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. The transplant date is indicated immediately after a transplant event is reported through the recipient feedback process in Waitlist and in the case of a living donor transplant, where a recipient was added through the donor feedback process in Tiedi.

State of Permanent Residence: Select the name of the state, of the recipient's permanent address, at the time of transplant.

Permanent Zip: Enter the recipient's zip code, of their permanent address, at the time of transplant.

Provider Information

Recipient Center: The recipient center will display. Verify the transplant center name and the center code, and the provider number, (6-character Medicare identification number of the hospital where the transplant recipient was transplanted) are correct.

Surgeon Name: Enter the name of the primary surgeon, who performed the transplant operation, and under whose name the transplant is billed.

NPI #: Enter the 10-character CMS (Center for Medicare and Medicaid Services, formerly HCFA) assigned National Provider Identifier of the transplant physician. Your hospital billing office may be able to obtain this number for you.

<div style="background:#c8c8c8;padding:2px">Donor Information</div>

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.

<div style="background:#c8c8c8;padding:2px">Patient Status</div>

Primary Diagnosis: Select the primary diagnosis **for the disease requiring a transplant** for this recipient at the time of transplant. If the recipient has had a previous transplant for the same organ type, select **Retransplant/Graft Failure** as the primary diagnosis for that organ. If **Other, Specify** is selected, enter the primary diagnosis in the space provided.

Date of: Report or Death: Enter the date the hospital reported the recipient as living, retransplanted (when the data was obtained prior to the recipient's discharge) or the date of the recipient's death, using the standard 8-digit numeric format of MM/DD/YYYY.

Patient Status: Select the appropriate status for this recipient. If **Dead** is selected, indicate the cause of death.

> **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.

> > **Contributory Cause of Death:** If the Patient Status is **Dead**, select the patient's contributory cause of death. Do not select the primary cause, since it cannot be both the primary and contributory cause of death. If an **Other** code is selected, enter the other cause of death in the space provided.

> > **Contributory Cause of Death:** If the Patient Status is **Dead**, select the patient's contributory cause of death. Do not select the primary cause, since it cannot be both the primary and contributory cause of death. If an **Other** code is selected, enter the other cause of death in the space provided.

> *Note:* If the patient is being retransplanted, access the patient's last record for their previous transplant and select **Retransplanted** in the **Patient Status** field. This will stop the generation of TRF records associated with the previous transplant.

Transplant Hospitalization:

> **Date of Admission to Tx Center:** Enter the date the recipient was admitted to the transplant center, using the standard 8-digit MM/DD/YYYY format.

> **Date of Discharge from Tx Center:** Enter the date the recipient was released to go home, using the standard 8-digit MM/DD/YYYY format. The recipient's hospital stay includes total time spent in different units of the hospital, including medical and rehab. This information is

not required in the TRR record, but if entered here, it will automatically fill in the future TRF records. It is required in the TRF record.

> *Note:* Leave this field blank if the recipient was removed from the waiting list with a code of 21, indicating the recipient died during the transplant procedure.

Was patient hospitalized during the last 90 days prior to the transplant admission? If the recipient was hospitalized during the last 90 days prior to transplant admission, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is optional.

Medical Condition at time of transplant: Select the choice that best describes the recipient's condition and location just prior to the time of transplant.

In Intensive Care Unit
Hospitalized Not in ICU
Not Hospitalized

Functional Status: Select the choice that best describes the recipient's functional status just prior to the time of transplant.

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

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

> *Note:* The Lansky Scale will display for pediatrics aged 1 to 17.

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

Physical Capacity: (Complete for recipients older than 18 years of age.) Select the choice that best describes the recipient's physical capacity at the time of listing. If the recipient's **Medical Condition** indicates they are hospitalized, select **Not Applicable (hospitalized)**. This field is optional for **adult** recipients only.

No Limitations
Limited Mobility
Wheelchair bound or more limited

Not Applicable (hospitalized)
Unknown

Physical Capacity is the ability to perform bodily activities such as walking, dressing, bathing, grooming, etc.

Cognitive Development: (Complete for recipients 18 years of age or younger.) Select the choice that best describes the recipient's cognitive development at the time of listing.

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 18 years of age or younger.) Select the choice that best describes the recipient's motor development at the time of listing.

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 19 years of age or older.) If the recipient is working for income just prior to the time of transplant, select **Yes**. If not, select **No**. If unknown, select **UNK**.

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

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

If No, Not Working Due To: If **No** is selected, indicate the reason why the recipient is not working at the time of listing. (This field is optional for **adult** recipients only.)

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

Academic Progress: (Complete for recipients 18 years of age or younger.) Select the choice that best describes the recipient's academic progress just prior to the time of transplant.

Within One Grade Level of Peers
Delayed Grade Level
Special Education
Not Applicable <5 years old
Status Unknown

Academic Activity Level: (Complete for recipients 18 years of age or younger.) Select the choice that best describes the recipient's academic activity level just prior to the time of transplant. If the recipient is less than 5 years old or has graduated from high school, select **Not Applicable < 5 years old/High School graduate**.

Full academic load
Reduced academic load
Unable to participate in academics due to disease or condition
Unable to participate regularly in academics due to dialysis (This selection is available to **pediatric** recipients only.)
Not Applicable <5 years old/High School graduate
Status Unknown

Source of Payment:

Primary: Select as appropriate to indicate the recipient's source of primary payment (largest contributor) for the transplant.

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/Choices/Overview.asp.

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 (i.e., 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/Choices/Overview.asp.

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 recipient will pay for the cost of transplant.

Donation indicates that a company, institution, or individual(s) donated funds to pay for the transplant and care of the recipient.

Free Care indicates that the transplant hospital will not charge recipient for the costs of the transplant operation.

Foreign Government, Specify refers to funds provided by a foreign government (Primary only) Specify foreign country in the space provided.

Secondary: Select check as appropriate to indicate the recipient's source of secondary payment. This field is optional.

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/Choices/Overview.asp.

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 (i.e., 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/Choices/Overview.asp.

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

Public insurance - Other government

Self indicates that the recipient will pay for the cost of transplant.

Donation indicates that a company, institution, or individual(s) donated funds to pay for the transplant and care of the recipient.

Free Care indicates that the transplant hospital will not charge the recipient for the costs of the transplant operation.

None - Select if the recipient does not have a secondary source of payment.

Clinical Information : Pretransplant

Previous Transplants: The three most recent transplant(s), indicated on the recipient's validated Transplant Recipient Registration (TRR) record(s), will display. Verify all previous transplants listed by organ type, transplant date and graft failure date.

Note: The three most recent transplants on record for this recipient will be displayed for verification. If there are any prior transplants that are not listed here, contact the UNet Helpdesk at 1-800-978-4334 or unethelpdesk@unos.org to determine if the transplant event is in the database.

Pretransplant Dialysis : If the recipient was on maintenance dialysis before transplant, select **Yes**. If not, select **No**. If unknown, select **UNK**.

> **If Yes, Date First Dialyzed:** If the recipient was on maintenance dialysis before transplant, enter the date that the recipient first began dialysis. If the date is unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

Serum Creatinine at Time of TX: Enter the serum creatinine, at the time of transplant, in mg/dl. If the value is unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

Viral Detection:

> **HIV Serostatus:** Select the serology results from the drop-down list.
>
> > **Positive**
> > **Negative**
> > **Not Done**
> > **UNK/Cannot Disclose**
>
> Definition: Human Immunodeficiency Virus - Any of several retroviruses and especially HIV-1 that infect and destroy helper T cells of the immune system causing the marked reduction in their numbers that is diagnostic of AIDS.

> **CMV IgG:** Select the serology results from the drop-down list.
>
> > **Positive**
> > **Negative**
> > **Not Done**
> > **UNK/Cannot Disclose**
>
> Definition: Cytomegalovirus - A herpesvirus (genus Cytomegalovirus) that causes cellular enlargement and formation of eosinophilic inclusion bodies especially in the nucleus and that acts as an opportunistic infectious agent in immunosuppressed conditions (as AIDS).

> **CMV IgM:** Select the serology results from the drop-down list.
>
> > **Positive**
> > **Negative**
> > **Not Done**
> > **UNK/Cannot Disclose**
>
> Definition: Cytomegalovirus - A herpesvirus (genus Cytomegalovirus) that causes cellular enlargement and formation of eosinophilic inclusion bodies especially in the nucleus and that acts as an opportunistic infectious agent in immunosuppressed conditions (as AIDS).

> **HBV Core Antibody:** Select the serology results from the drop-down list.
>
> > **Positive**
> > **Negative**
> > **Not Done**
> > **UNK/Cannot Disclose**
>
> Definition: Hepatitis B Virus - A sometimes fatal hepatitis caused by a double-stranded DNA virus (genus Orthohepadnavirus of the family Hepadnaviridae) that tends to persist in the blood serum and is transmitted especially by contact with infected blood (as by transfusion or by sharing contaminated needles in illicit intravenous drug use) or by contact with other infected bodily fluids (as during sexual intercourse) -- also called serum hepatitis.

> **HBV Surface Antigen:** Select the serology results from the drop-down list.

Positive
Negative
Not Done
UNK/Cannot Disclose

Definition: Hepatitis B Virus - A sometimes fatal hepatitis caused by a double-stranded DNA virus (genus Orthohepadnavirus of the family Hepadnaviridae) that tends to persist in the blood serum and is transmitted especially by contact with infected blood (as by transfusion or by sharing contaminated needles in illicit intravenous drug use) or by contact with other infected bodily fluids (as during sexual intercourse) -- also called serum hepatitis.

HCV Serostatus: Select the serology results from the drop-down list.

Positive
Negative
Not Done
UNK/Cannot Disclose

Definition: Hepatitis C Virus - A disease caused by a flavivirus that is usually transmitted by parenteral means (as injection of an illicit drug, blood transfusion, or exposure to blood or blood products) and that accounts for most cases of non-A, non-B hepatitis.

EBV Serostatus: Select the serology results from the drop-down list.

Positive
Negative
Not Done
UNK/Cannot Disclose

Definition: (Epstein-Barr Virus) - A herpesvirus (genus Lymphocryptovirus) that causes infectious mononucleosis and is associated with Burkitt's lymphoma and nasopharyngeal carcinoma -- abbreviation EBV; called also EB virus.

<u>Was preimplantation kidney biopsy performed at the transplant center</u>: If a pre-implantation kidney biopsy was performed, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is optional.

<u>Did patient receive any pretransplant blood transfusions</u>: If the recipient received any pretransplant blood transfusions between listing and transplant, select **Yes**. If not, select **No**. If unknown, select **UNK**.

<u>Any tolerance induction technique used</u>: If the recipient used any tolerance induction technique, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is optional.

Tolerance Induction: Before a transplant occurs the immune system can be prepared for the upcoming graft by attempting to induce graft tolerance. This can be achieved through a variety of protocols. The following are examples of tolerance induction protocols from the Primer on Transplantation 1-4)*:

Administration of moAbs (monoclonal antibodies) targeting cell surface molecules such as CD4, CD8, CD25, LFA-1, or the TCR (T-cell receptor)

Blockade of the costimulation pathways of T cell activation

Institution of pharmacological drug including steroids, rapamycin, cyclosporine

Donor specific transfusion

Combinations of immunosuppressive drugs and plasmaphoresis to decrease the recipient PRA in living donor transplants (member example)

* Norman, Douglas J., Turka, Laurence A. Primer on Transplantation, Second Edition page 40, American Society of Transplantation 2001

Previous Pregnancies: (This field will not display for male recipients) Select the number of previous pregnancies. Previous pregnancies include pregnancies, which may not have resulted in live births. If the information is unknown, select **Unknown**. (This field is optional for **pediatric** recipients only.)

> **No Previous Pregnancy**
> **1 Previous Pregnancy**
> **2 Previous Pregnancies**
> **3 Previous Pregnancies**
> **4 Previous Pregnancies**
> **5 Previous Pregnancies**
> **More than 5 Previous Pregnancies**
> **Not Applicable: < 10 years old**
> **Unknown**

Malignancies between listing and transplant: If recipient had any malignancies between listing and transplant, select **Yes**. If the recipient has not had any malignancies, select **No**. If **Yes** is selected, indicate type of malignancy. If the recipient had a malignancy, but the type of malignancy is not listed, select **Other, specify** and enter the name of the malignancy in the space provided.

> **Skin Melanoma**
> **Skin Non-Melanoma**
> **CNS Tumor**
> **Genitourinary**
> **Breast**
> **Thyroid**
> **Tongue/Throat/Larynx**
> **Lung**
> **Leukemia/Lymphoma**
> **Liver**
> **Other, specify**

> *Note:* This question is NOT applicable for patients receiving living donor transplants who were never on the waiting list.

Is Growth Hormone Therapy Used between listing and transplant: (Complete for recipients 18 years of age or younger.) If the recipient is undergoing growth hormone therapy, select **Yes**. If not, select **No**. If unknown, select **UNK**.

Bone Disease (check all that apply): (Complete for recipients 18 years of age or younger.)

> **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**.

Clinical Information : Transplant Procedure

Multiple Organ Recipient: If the recipient received other organs, reported on the Recipient Feedback, they will display. If the recipient didn't receive any other organs at this time, None is

displayed. Verify the other organs, transplanted at this time, are correct. If incorrect, contact the Help Desk at 1-800-978-4334.

Were extra vessels used in the tx procedure: If extra vessels (vascular allografts) were used in the transplant procedure, as indicated on the Waitlist Removal, **Yes** displays.

> **Vessel Donor ID:** The Donor ID entered on the Waitlist Removal displays.

> > *Note:* If the extra vessels used in a transplant procedure are procured from a tissue processing organization, they are not reported in UNet.

Procedure Type: Verify the procedure type is correct.

> **Left Kidney**: The recipient received a single left kidney.
> **Right Kidney**: The recipient received a single right kidney.
> **En-Bloc**: The recipient received both kidneys from the same donor, which were transplanted en-bloc or together.
> **Sequential**: The recipient received both kidneys from the same donor, which were transplanted separately.
> **Hemi-Renal**: The recipient received a split kidney.

Kidney Preservation Information:

> *Note:* Enter the time in hours and decimal parts of an hour. For example, 1 hour should be entered as "1", "1.0" or "1.00"; 1 hour and 30 minutes should be entered as "1.5" or "1.50" **not "1.30"**.

> **Total Cold Ischemia Time Right KI (or En-Bloc): (if pumped, include pump time):** If the recipient's Procedure Type is **Right Kidney**, **En-Bloc**, **Sequential**, or **Hemi-Renal**, enter the **Total Cold Ischemia Time** for the right kidney or both kidneys, in hours, (if pumped, include pump time). If the time is unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

> **-OR-**

> **Total Cold Ischemia Time Left KI: (if pumped, include pump time):** If the recipient's Procedure Type is **Single Left**, **Sequential**, or **Hemi-Renal**, enter the **Total Cold Ischemia Time** for the left kidney, in hours, (if pumped, include pump time). If the time is unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

> > **Total Cold Ischemia Time** is the number of hours between the time preservation of the organ begins and the time the organ was removed from cold storage.

> **Total Warm Ischemia Time Right KI (or En-Bloc): (include anastomotic time):** If the recipient's Procedure Type is **Right Kidney**, **En-Bloc**, **Sequential**, or **Hemi-Renal**, enter the **Warm Ischemia Time** for the right kidney or both kidneys, in minutes, (include anastomotic time) for the right or en-bloc kidneys. (This field is optional for **adult** recipients only.) If the time is unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). This field is optional.

> **-OR-**

> **Total Warm Ischemia Time Left KI (or En-Bloc): (include anastomotic time):** If the recipient's Procedure Type is **Single Left**, **Sequential**, or **Hemi-Renal**, enter the **Warm Ischemia Time** for the left kidney, in minutes, (include anastomotic time) for the right or en-bloc kidneys. (This field is optional for **adult** recipients only.) If the time is unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**). This field is optional.

Kidney(s) received on: Indicate whether the transplanted organs were received on **Ice** or **Pump**. For recipients of a living donor transplant, **N/A** is also an option. If received on ice, indicate whether the organ(s) **Stayed on ice** or were **Put on pump**. If received on pump, indicate whether the organ(s) **Stayed on pump** or were **Put on ice**.

Note: Select **N/A** from the **ST** field for all Preservation Information if the recipient was removed from the waiting list with a code 21, indicating the recipient died during the transplant procedure.

If put on pump or stayed on pump: If the organs were pumped, indicate the **Final resistance at transplant** and **Final flow rate at transplant** (this field is optional) in the spaces provided. This field will not display if transplanted organs were received on **Ice** and **Stayed on ice**.

<u>**Incidental Tumor found at time of Transplant:**</u> If an incidental tumor was found at the time of transplant in an organ that was removed from the recipient, select **Yes**. If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, specify the tumor type. If **Other Primary Kidney Tumor, Specify** is selected, enter the name in the space provided. These fields are optional.

> **Oncocytoma**
> **Renal Cell Carcinoma**
> **Carcinoid**
> **Adenoma**
> **Transitional Cell Carcinoma**
> **Other Primary Kidney Tumor, Specify**

Clinical Information : Post Transplant

<u>**Graft Status:**</u> If the kidney graft is functioning, select **Functioning**. If the graft is not functioning at the time of hospital discharge or time of report, select **Failed**. If failed, complete the remainder of this section.

Note: Select **Functioning** if the recipient was removed from the waiting list with a code 21, indicating the recipient died during the transplant procedure.

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 section:

Resumed Maintenance dialysis: If the recipient returned to maintenance dialysis, select **Yes**. If not, select **No**.

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

Select a Dialysis Provider:

Provider #: If the recipient returned to maintenance dialysis, enter the provider. This field is optional.

Provider Name: Enter the name of the dialysis provider. This field is optional.

Note: You may re-sort your Provider or Center results by clicking the designated red drop-down arrow.

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

Kidney Primary Cause of Graft Failure: Select the primary cause of graft failure. If the primary cause of graft failure is not listed, select **Other Specify Cause** and enter the primary cause of graft failure in the space provided.

> **Hyperacute Rejection**
> **Acute Rejection**
> **Primary Failure**
> **Graft Thrombosis**
> **Infection**
> **Surgical Complications**

<p style="margin-left: 2em">**Urological Complications**
Recurrent Disease
Other Specify Cause</p>

<p style="margin-left: 1.5em">**Contributory causes of graft failure:** For each of the causes listed, select **Yes**, **No**, or **Unk** to indicate if each is a contributory cause of graft failure. Select **No** for the primary cause, since it cannot be both the primary and secondary cause of graft failure. If a cause other than those listed contributed to the graft failure, enter the contributory cause of graft failure in the **Other** space provided. These fields are optional.</p>

<p style="margin-left: 2em">**Kidney Acute Rejection**
Kidney Graft Thrombosis
Kidney Infection
Surgical Complications
Urological Complications
Recurrent Disease
Other</p>

Most Recent Serum Creatinine Prior to Discharge: Enter the most recent serum creatinine value in mg/dl available prior to the recipient's discharge from the hospital. If the value is unavailable, select the appropriate status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

Kidney Produced >40 ml of Urine in First 24 hours? If the kidney graft produced at least 40 ml of urine within the first 24 hours following the transplant operation, select **Yes**. If not, select **No**. This field is optional.

Patient Need dialysis within First Week? If the recipient required any dialysis within the first 7 days following the transplant operation, select **Yes**. If not, select **No**.

Creatinine decline by 25% or more in first 24 hours on 2 separate samples: If creatinine value declined by 25% or more in the first 24 hours post transplant on 2 separate samples, select **Yes**. If not, select **No**. This field is optional.

Did patient have any acute rejection episodes between transplant and discharge: If the recipient had any acute rejection episodes between transplant and discharge, select a Yes choice. If not, select No. If a Yes choice is selected, then indicate if a biopsy was done to confirm acute rejection.

<p style="margin-left: 1.5em">**Yes, at least one episode treated with anti-rejection agent**
Yes, none treated with additional anti-rejection agent
No</p>

<p style="margin-left: 1.5em">**Was Biopsy done to confirm acute rejection:** If the recipient had an acute kidney rejection episode, indicate whether biopsy confirmed acute rejection by selecting **Yes**. If a biopsy was not done, select **Biopsy not done**. If unknown, select **Unknown**. This field is optional.</p>

<p style="margin-left: 2em">**Biopsy not done**
Yes, rejection confirmed
Yes, rejection not confirmed</p>

Date of Measurement: (Complete for recipients 18 years of age or younger.) Enter the date, using the 8-digit format of MM/DD/YYYY, the recipient's height and weight were measured.

Height: Enter the height of the recipient at the time of discharge 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**). For recipients 18 years old or

younger at the time of listing, UNet will generate and display calculated percentiles based on the 2000 CDC growth charts.

Weight: Enter the weight of the recipient at the time of discharge 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**). For recipients 18 years old or younger at the time of listing, UNet will generate and display calculated percentiles based on the 2000 CDC growth charts.

BMI (Body Mass Index): The recipient's BMI will display. For recipients 18 years old or younger, at the time of listing, 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/.

Treatment

Biological or Anti-viral Therapy: If biological or anti-viral therapy is being administered to the recipient, select **Yes**. If not, select **No**. If unknown or can't disclose, select **Unknown/Cannot Disclose**. If **Yes** is selected, check all that apply. If a therapy, other than those listed, was administered, select **Other, Specify** and enter the therapy in the space provided. These fields are optional.

> **Acyclovir (Zovirax)**
> **Cytogam (CMV)**
> **Gamimune**
> **Gammagard**
> **Ganciclovir (Cytovene)**
> **Valgancyclovir (Valcyte)**
> **HBIG (Hepatitis B Immune Globulin)**
> **Flu Vaccine (Influenza Virus)**
> **Lamivudine (Epivir) (for treatment of Hepatitis B)**
> **Valacyclovir (Valtrex)**
> **Other, Specify**

Other Therapies: If the recipient received other therapies, select **Yes**. If not, select **No**. If **Yes** is selected, check all that apply. These fields are optional.

> **Photopheresis**
> **Plasmapheresis**
> **Total Lymphoid Irradiation (TLI)**

Note: If the recipient was removed from the waiting list with a code 21, indicating the recipient died during the transplant procedure, select **No** for all Biologicals or Anti-viral.

Immunosuppressive Information

Are any medications given currently for maintenance or anti-rejection: If medications have been given to the recipient for maintenance or anti-rejection during the time between transplant and hospital discharge, or 6 weeks post-transplant if the recipient has not been discharged, select **Yes**. If not, select **No**. If **Yes**, complete the sections below.

Did the recipient participate in any clinical research protocol for immunosuppressive medications: If the recipient participated in clinical research for immunosuppressive

medications, select **Yes**. If not, select **No**. If **Yes**, specify in the space provided. These fields are optional.

Immunosuppressive Medications

For each of the immunosuppressive medications listed, select **Ind. (Induction)**, **Maint (Maintenance)** or **AR (Anti-rejection)** to indicate all medications that were prescribed for the recipient during the initial transplant hospitalization period, and for what reason. If a medication was not given, leave the associated box blank.

Induction (Ind.) immunosuppression includes all medications given for a short finite period in the perioperative period for the purpose of preventing acute rejection. Though the drugs may be continued after discharge for the first 30 days after transplant, it will not be used long-term for immunosuppressive maintenance. Induction agents are usually polyclonal, monoclonal, or IL-2 receptor antibodies (e.g., Methylprednisolone, Atgam, Thymoglobulin, OKT3, Simulect, or Zenapax). Some of these drugs might be used for another finite period for rejection therapy and would be recorded as rejection therapy if used for this reason. For each induction medication indicated, enter the total number of days the drug was actually administered in the space provided. For example, if Simulect or Zenapax was given in 2 doses a week apart then the total number of days would be 2, even if the second dose was given after the patient was discharged.

Maintenance (Maint) includes all immunosuppressive medications given before, during or after transplant for varying periods of time which may be either long-term or intermediate term with a tapering of the dosage until the drug is either eliminated or replaced by another long-term maintenance drug (e.g., Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). This does not include any immunosuppressive medications given to treat rejection episodes, or for induction.

Anti-rejection (AR) immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode during the initial post-transplant period or during a specific follow-up period, usually up to 30 days after the diagnosis of acute rejection (e.g., Methylprednisolone, Atgam, OKT3, or Thymoglobulin). When switching maintenance drugs (e.g., 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: As further clarification, drugs that are used with the intention to maintain recipients long-term are medications such as Tacrolimus, Cyclosporine, Azathioprine, Mycophenolate Mofetil and Prednisone. These maintenance medications should not be listed as AR medications to treat acute rejection. When patients have a true acute rejection, they are given anti-rejection medication such as steroids, OKT3, ATG, Simulect and Zenapax, in addition to the maintenance medications. These are the medications that should be selected as anti-rejection.

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

If the number of days is unavailable, select the appropriate status from the applicable **Status** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

Other Immunosuppressive Medications

For each of the immunosuppressive medications listed, select **Ind. (Induction)**, **Maint (Maintenance)** or **AR (Anti-rejection)** to indicate all medications that were prescribed for the recipient during the initial transplant hospitalization period, and for what reason. If a medication was not given, leave the associated box blank.

Induction (Ind.) immunosuppression includes all medications given for a short finite period in the perioperative period for the purpose of preventing acute rejection. Though the drugs may be continued after discharge for the first 30 days after transplant, it <u>will not</u> be used long-term for immunosuppressive maintenance. Induction agents are usually polyclonal, monoclonal, or IL-2 receptor antibodies (e.g., Methylprednisolone, Atgam, Thymoglobulin, OKT3, Simulect, or Zenapax). Some of these drugs might be used for another finite period for rejection therapy and would be recorded as rejection therapy if used for this reason. For each induction medication indicated, enter the <u>total number of days the drug was actually administered</u> in the space provided. For example, if Simulect or Zenapax was given in 2 doses a week apart then the total number of days would be 2, even if the second dose was given after the patient was discharged.

Maintenance (Maint) includes all immunosuppressive medications given before, during or after transplant for varying periods of time which may be either long-term or intermediate term with a tapering of the dosage until the drug is either eliminated or replaced by another long-term maintenance drug (e.g., Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). This does not include any immunosuppressive medications given to treat rejection episodes, or for induction.

Anti-rejection (AR) immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode during the initial post-transplant period or during a specific follow-up period, usually up to 30 days after the diagnosis of acute rejection (e.g., Methylprednisolone, Atgam, OKT3, or Thymoglobulin). When switching maintenance drugs (e.g., from Tacrolimus to Cyclosporine; or from Mycophenolate Mofetil to Azathioprine) because of rejection, the drugs <u>should not</u> be listed under AR immunosuppression, but <u>should be</u> listed under maintenance immunosuppression.

> *Note:* As further clarification, drugs that are used with the intention to maintain recipients long-term are medications such as Tacrolimus, Cyclosporine, Azathioprine, Mycophenolate Mofetil and Prednisone. These maintenance medications should not be listed as AR medications to treat acute rejection. When patients have a true acute rejection, they are given anti-rejection medication such as steroids, OKT3, ATG, Simulect and Zenapax, in addition to the maintenance medications. These are the medications that should be selected as anti-rejection.

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

If the number of days is unavailable, select the appropriate status from the applicable **Status** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

Investigational Immunosuppressive Medications

For each of the immunosuppressive medications listed, select **Ind. (Induction)**, **Maint (Maintenance)** or **AR (Anti-rejection)** to indicate all medications that were prescribed for the recipient during the initial transplant hospitalization period, and for what reason. If a medication was not given, leave the associated box blank.

Induction (Ind.) immunosuppression includes all medications given for a short finite period in the perioperative period for the purpose of preventing acute rejection. Though the drugs may be continued after discharge for the first 30 days after transplant, it <u>will not</u> be used long-term for immunosuppressive maintenance. Induction agents are usually polyclonal, monoclonal, or IL-2 receptor antibodies (example: Methylprednisolone, Atgam, Thymoglobulin, OKT3, Simulect, or Zenapax). Some of these drugs might be used for another finite period for rejection therapy and would be recorded as rejection therapy if

used for this reason. For each induction medication indicated, enter the <u>total number of days the drug was actually administered</u> in the space provided. For example, if Simulect or Zenapax was given in 2 doses a week apart then the total number of days would be 2, even if the second dose was given after the patient was discharged.

Maintenance (Maint) includes all immunosuppressive medications given before, during or after transplant for varying periods of time which may be either long-term or intermediate term with a tapering of the dosage until the drug is either eliminated or replaced by another long-term maintenance drug (e.g., Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). This does not include any immunosuppressive medications given to treat rejection episodes, or for induction.

Anti-rejection (AR) immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode during the initial post-transplant period or during a specific follow-up period, usually up to 30 days after the diagnosis of acute rejection (example: Methylprednisolone, Atgam, OKT3, or Thymoglobulin). When switching maintenance drugs (example: from Tacrolimus to Cyclosporine; or from Mycophenolate Mofetil to Azathioprine) because of rejection, the drugs <u>should not</u> be listed under AR immunosuppression, but <u>should be</u> listed under maintenance immunosuppression.

> *Note:* As further clarification, drugs that are used with the intention to maintain recipients long-term are medications such as Tacrolimus, Cyclosporine, Azathioprine, Mycophenolate Mofetil and Prednisone. These maintenance medications should not be listed as AR medications to treat acute rejection. When patients have a true acute rejection, they are given anti-rejection medication such as steroids, OKT3, ATG, Simulect and Zenapax, in addition to the maintenance medications. These are the medications that should be selected as anti-rejection.

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

If the number of days is unavailable, select the appropriate status from the applicable **Status** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

<u>**Drug Codes**</u>

Sandimmune (Cyclosporine A)
Neoral (CyA-NOF)
Tacrolimus (Prograf, FK506)
Sirolimus (RAPA, Rapamycin, Rapamune)
Leflunomide (LFL, Arava)
Azathioprine (AZA, Imuran)
Mycophenolate Mofetil (MMF, Cellcept, RS61443)
Cyclophosphamide (Cytoxan)
Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)
Atgam (ATG)
OKT3 (Orthoclone, Muromonab)
Thymoglobulin
Zenapax - Daclizumab
Simulect - Basiliximab
Gengraf (Abbott Cyclosporine)
Everolimus (RAD, Certican)
EON (Generic Cyclosporine)
Myfortic (Mycophenolate Sodium)
Other generic Cyclosporine, specify brand:

Steroids (Prednisone,Methylprednisolone,Solumedrol,Medrol,Decadron)
Campath - Alemtuzumab (anti-CD52)
FTY 720
Rituximab
Modified Release Tacrolimus FK506E (MR4)
Other Immunosuppressive Medication, Specify
Other Immunosuppressive Medication, Specify