# Thoracic Transplant Recipient Registration (TRR) Record Field Descriptions

The Transplant Recipient Registration (TRR) records are generated and available immediately after a transplant event is reported through the recipient feedback process in Waitlist<sup>SM</sup>. 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<sup>SM</sup>. The 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 is first. If the recipient is still hospitalized at six weeks post transplant, provide the most recent information available regarding the recipient's progress.

The TRR record must be completed within 60 days from the record generation date. See <a href="OPTN/UNOS Policies">OPTN/UNOS Policies</a> 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.

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

<u>HIC</u>: Verify the 9 to 11 character Health Insurance Claim number for the recipient indicated on the recipient's <u>most recently</u> 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.

<u>State of Permanent Residence</u>: Select the name of the state of the recipient's permanent address at the time of transplant (location of full-time residence, not transplant center location). This field is **required**. (Appendix A)

<u>Permanent Zip</u>: Enter the recipient's permanent zip code at the time of transplant (location of full-time residence, not transplant center location). This field is **required**.

#### **Provider Information**

<u>Recipient Center</u>: 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.

Physician Name: Enter the name of the physician who is following the patient. This field is required.

<u>Physician NPI #</u>: Enter the 10-character CMS (Center for Medicare and Medicaid Services) assigned National Provider Identifier of the transplant physician. Your hospital billing office may be able to obtain this number for you. This field is **required**.

<u>Surgeon Name</u>: Enter the name of the primary surgeon, who performed the transplant operation, and under whose name the transplant is billed. This field is **required**.

<u>Surgeon NPI #</u>: Enter the 10-character CMS (Center for Medicare and Medicaid Services) assigned National Provider Identifier of the transplant surgeon. Your hospital billing office may be able to obtain this number for you. This field is **required**.

#### **Donor Information**

<u>UNOS Donor ID #</u>: 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.

**Recovering OPO:** The Organ Procurement Organization (OPO) code will display. Verify the code is correct.

**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**

<u>Primary Diagnosis</u>: Select the primary diagnosis for the disease requiring a transplant for this recipient. If the recipient has had a previous transplant for the same organ type, enter Retransplant/Graft Failure as the primary diagnosis for that organ. If Other, Specify is selected, enter the primary diagnosis in the space provided. This field is required. (<u>Appendix F</u>) For definitions of the diagnosis codes, please see the OPTN website.

<u>Date: Last Seen, Retransplanted, or Death</u>: Complete at discharge (if discharged prior to six weeks from transplant date) or at six weeks from transplant date, whichever occurs first. 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. This field is **required**.

<u>Patient Status</u>: Complete at discharge (if discharged prior to six weeks from transplant date) or at six weeks from transplant date, whichever occurs first. Select the appropriate status for this recipient. If **Dead** is selected, indicate the cause of death. This field is **required**.

Living Dead

Retransplanted

**Primary Cause of Death:** If the Patient Status is **Dead**, select the patient's cause of death. If an **Other** code is selected, enter the other cause of death in the space provided. (<u>Appendix M</u>)

**Contributory Cause of Death:** If the Patient Status is **Dead**, select the patient's contributory cause of death. If an **Other** code is selected, enter the other cause of death in the space provided. (Appendix J)

Contributory Cause of Death: If the Patient Status is Dead, select the patient's contributory cause of death. If an **Other** code is selected, enter the other cause of death in the space provided. (Appendix J)

**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 8-digit MM/DD/YYYY format. If the patient was admitted to the hospital before it was determined a transplant was needed, enter the date it was determined the patient needed a transplant. This field is **required**.

Date of Discharge from Tx Center: Enter the date the recipient was released to go home, using the 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.

#### **Clinical Information: PRETRANSPLANT**

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. This field is **required**.

IN INTENSIVE CARE UNIT - Patient was hospitalized and in the ICU prior to transplant preparation and the actual transplant.

**HOSPITALIZED NOT IN ICU** - Patient was hospitalized but not in the ICU prior to transplant preparation and the actual transplant.

NOT HOSPITALIZED - Patient was not hospitalized prior to transplant preparation and the actual transplant.

Patient on Life Support: If the recipient was on life support at the time of transplant, select Yes. If not, select No. If Yes is selected, select life support types that apply. If Other Mechanism is selected, enter the type of mechanism in the space provided. This field is **required**.

(Heart Only)

**Extra Corporeal Membrane Oxygenation Intra Aortic Balloon Pump Prostaglandins Intravenous Inotropes Inhaled NO Ventilator** - Select only if the recipient is on continuous invasive ventilation. Other mechanism

(Lung and Heart/Lung Only)

**Extra Corporeal Membrane Oxygenation Intra Aortic Balloon Pump Prostacyclin Infusion Prostacyclin Inhalation** Inhaled NO

**Ventilator -** Select only if the recipient was on continuous invasive ventilation.

IV Inotropes (pediatric recipients only)
Other Mechanism

<u>Patient on Ventricular Assist Device</u>: If the candidate was on a Ventricular Assist Device (VAD) at the time of transplant, select the type. If the candidate was not on a VAD, select **None**. This field is **required**.(<u>Appendix B</u>)

If a VAD was indicated, select the brand of device that the candidate was on. If **LVAD+RVAD** was indicated, select the brand of device the candidate was on for both **LVAD** and **RVAD**. If **Other**, **Specify** is selected for one of the following, specify the name in the space provided.

#### LVAD:

Abiomed AB5000

Abiomed BVS 5000 Berlin Heart EXCOR

Diamediana

**Biomedicus** 

**Cardiac Assist Tandem Heart** 

CentriMag (Thoratec/Levitronix)

**Evaheart** 

**Heartmate II** 

**Heartmate XVE** 

**Heartsaver VAD** 

**Heartware HVAD** 

Impella Recover 2.5

Impella Recover 5.0

Jarvik 2000

**Maguet Josta Rotaflow** 

Medos

MicroMed DeBakey

MicroMed DeBakey - Child

PediMag (Thoratec/Levitronix)

**Terumo DuraHeart** 

**Thoratec IVAD** 

**Thoratec PVAD** 

Tovobo

**Ventracor VentrAssist** 

**Worldheart Levacor** 

Other, Specify

#### RVAD:

Abiomed AB5000

Abiomed BVS 5000

**Berlin Heart EXCOR** 

**Biomedicus** 

**Cardiac Assist Tandem Heart** 

CentriMag (Thoratec/Levitronix)

**Evaheart** 

**Heartmate II** 

**Heartmate XVE** 

**Heartsaver VAD** 

**Heartware HVAD** 

Impella Recover 2.5

Impella Recover 5.0

Jarvik 2000

**Maguet Josta Rotaflow** 

Medos

MicroMed DeBakey
MicroMed DeBakey - Child
PediMag (Thoratec/Levitronix)
Terumo DuraHeart
Thoratec IVAD
Thoratec PVAD
Toyobo
Ventracor VentrAssist
Worldheart Levacor
Other, Specify

#### TAH:

AbioCor SynCardia CardioWest Other, Specify

#### LVAD + RVAD:

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

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 guiet 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.

<u>Cognitive Development</u>: (This field is **required** for recipients 18 years of age or younger.) Select the choice that best describes the recipient's cognitive development just prior to the time of transplant.

**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:** (This field is **required** for recipients 18 years of age or younger.) Select the choice that best describes the recipient's motor development just prior to the time of transplant.

**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** 

<u>Academic Progress</u>: (This field is **required** for recipients less than 18 years of age.) Select the choice that best describes the recipient's academic progress 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 or GED.** 

Within One Grade Level of Peers
Delayed Grade Level
Special Education
Not Applicable <5 years old/High School graduate or GED
Status Unknown

<u>Academic Activity Level</u>: (This field is **required** for recipients less than 18 years of age.) 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 or GED**.

Full academic load
Reduced academic load
Unable to participate in academics due to disease or condition
Not Applicable <5 years old/High School graduate or GED
Status Unknown

<u>Working for income</u>: (This field is **required** for recipients 18 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**.

#### **Source of Payment:**

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

**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 <a href="http://www.medicare.gov/">http://www.medicare.gov/</a>.

**Public insurance - Medicare & Choice** 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 <a href="http://www.medicare.gov/">http://www.medicare.gov/</a>.

**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. (<u>Appendix E</u>)

**<u>Date of Measurement</u>**: (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.

<u>Height</u>: Enter the height of the recipient, just prior to the time of transplant, in feet and inches or centimeters. If the recipient's height is unavailable, select the appropriate status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**). For recipients 18 years old or younger at the time of transplant, UNet will generate and display calculated percentiles based on the 2000 CDC growth charts. This field is **required**.

<u>Weight</u>: Enter the weight of the recipient, just prior to the time of transplant, in pounds or kilograms. If the recipient's weight is unavailable, select the appropriate status from the **ST** field (**Missing**, **Unknown, N/A**, **Not Done**). For recipients 18 years old or younger at the time of transplant, UNet will generate and display calculated percentiles based on the 2000 CDC growth charts. This field is required.

**BMI (Body Mass Index):** The recipient's BMI will display. For candidates less than 20 years of age at the time of transplant, 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 weightfor-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 <a href="http://www.cdc.gov/">http://www.cdc.gov/</a>.

**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.

<u>Previous Transplants</u>: 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 Help Desk at 1-800-978-4334 or <a href="mailto:unethelpdesk@unos.org">unethelpdesk@unos.org</a> to determine if the transplant event is in the database.

#### **Viral Detection:**

**HIV Serostatus:** Select the serology results from the list. This field is **required**.

**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.

Nucleic Acid Testing (NAT) HIV- Select the NAT results from the list. This field is required

**Positive** 

**Negative** 

**Not Done** 

**UNK/Cannot Disclose** 

**CMV Status:** Select the serology results from the list. If there is a positive CMV IgG or positive CMV Total Antibody result then CMV Status should be reported as positive. This field is **required**.

**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 Surface Antibody Total: Select the serology results from the list. This field is required.

**Positive** 

**Negative** 

**Not Done** 

**UNK/Cannot Disclose** 

**HBV Core Antibody:** Select the serology results from the list. This field is **required**.

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

**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.

Nucleic Acid Testing (NAT) HBV- Select the NAT results from the list. This field is required

Positive Negative Not Done UNK/Cannot Disclose

**HCV Serostatus:** Select the serology results from the list. This field is **required**.

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.

Nucleic Acid Testing (NAT) HCV- Select the NAT results from the list. This field is required

Positive Negative Not Done UNK/Cannot Disclose

**EBV Serostatus:** Select the serology results from the list. This field is **required**.

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>Most Recent Hemodynamics</u>: Enter the most recent hemodynamic values. For each measure, indicate if the measurement was obtained while the recipient was on Inotropes or Vasodilators. If the tests were not done, select **Not Done** in the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**).

PA (sys) mm/Hg - systolic pulmonary artery pressure. This field is required.

PA (dia) mm/Hg - diastolic pulmonary artery pressure. This field is required.

PA (mean) mm/Hg - mean pulmonary artery pressure. This field is required.

PCW (mean) mm/Hg - mean pulmonary capillary wedge pressure. This field is required.

**CO** L/min - cardiac output. This field is required.

**Cardiac Index** will be calculated and displayed for pediatric recipients.

<u>Most Recent Serum Creatinine</u>: Enter the most recent pre-transplant serum creatinine lab value in mg/dl. If the value is not available, select the appropriate status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**). This field is **required**.

<u>Most Recent Serum Total Bilirubin</u>: Enter the most recent pre-transplant serum total bilirubin lab value in mg/dl. If the value is not available, select the appropriate status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**). This field is **required**.

<u>Chronic Steroid Use</u>: If the recipient required chronic steroid use prior to transplantation, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

<u>Pulmonary Status</u> (<u>Lung and Heart/Lung Only</u>): Give most recent value. Enter the most recent pulmonary function values. If the values are not available, select the appropriate status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**).

**FVC** - forced vital capacity (% predicted). This field is **required**.

**FeV1** - forced expiratory volume at one second (% predicted). This field is **required**.

pCO2 - partial carbon dioxide pressure. This field is required.

#### **Events occurring between listing and transplant:**

For each of the events listed, indicate if the event occurred between the time the recipient was placed on the OPTN/UNOS thoracic organ waiting list and the date of transplant.

**Transfusions:** If the recipient received any blood or blood product transfusions between listing and transplant, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

**Pulmonary Embolism: (Lung only)** If the recipient experienced any episode of pulmonary embolism between listing and transplant, select **Yes**. If not, select **No**. If unknown, select **UNK**.

**Infection Requiring IV Therapy within 2 wks prior to Tx:** If the recipient experienced any infection requiring treatment with intravenous antibiotics during the two week period immediately prior to transplantation, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

**Dialysis:** If the recipient had any hemodialysis or peritoneal dialysis between listing and transplant, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

**Prior Cardiac Surgery (non-transplant):** If the recipient had cardiac surgery between the time the recipient was placed on the OPTN/UNOS thoracic organ waiting list and the date of transplant, select **Yes.** If no prior cardiac surgery, select **No.** If unknown, select **UNK**. If **Yes** is selected, select all type(s) of surgery. If the type of cardiac surgery is not listed, select **Other, specify** and enter the type of cardiac surgery in the space provided. This field is **required**.

CABG
Valve Replacement/Repair
Congenital
Left Ventricular Remodeling
Other, specify

**Prior Lung Surgery (non-transplant):** If the recipient had lung surgery between the time the recipient was placed on the OPTN/UNOS thoracic organ waiting list and the date of transplant, select **Yes**. If no prior lung surgery, select **No**. If unknown, select **UNK**. If **Yes** is selected, select all type(s) of surgery. If the type of lung surgery is not listed, select **Other, specify** and enter the type of cardiac surgery in the space provided. This field is **required**.

Pneumoreduction
Pneumothorax Surgery-Nodule
Pneumothorax Decortication
Lobectomy
Pneumonectomy
Left Thoracotomy
Right Thoracotomy
Other, specify

**Episode of Ventilatory Support:** If the recipient experienced continuous invasive ventilation between listing and transplant, select **Yes**. If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, indicate the most recent timeframe. This field is **required**.

**If yes, indicate most recent timeframe:** If the recipient had an episode of ventilator support, select the most recent timeframe.

At time of transplant
Within 3 months of transplant
> 3 months prior to transplant

<u>Tracheostomy</u> (Lung and Heart/Lung Only): If the recipient had a tracheostomy, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

[PEDIATRIC RECIPIENTS]

<u>Prior Thoracic Surgery Other Than Prior Transplant</u>: If the recipient had thoracic surgery prior to listing, select **Yes**. If no prior thoracic surgery, select **No**. If **Yes** is selected, select all type(s) of surgery. If the type of thoracic surgery is not listed, select **Other**, **specify** and enter the type of thoracic surgery in the space provided.

If yes, number of prior sternotomies:	
0	
1	
2	
3	
4	
5+	

**Unknown number of prior sternotomies** 

If yes, number of prior thoracotomies

0

1

2

3

4

5+

Unknown number of prior thoracotomies

**Prior Congenital Cardiac Surgery:** If the recipient had prior surgery, select **Yes**. If not, select **No**. If unknown, select **UNK**.

If Yes, palliative surgery: If the surgery was palliative, select Yes. If not, select No. If unknown, select UNK.

If Yes, corrective surgery: If the surgery was corrective, select Yes. If not, select No. If unknown, select UNK.

**If Yes, single ventricular physiology:** If the surgery was to correct single ventricular physiology, select **Yes**. If not, select **No**. If unknown, select **UNK**.

#### **Pretransplant Titer Information:**

Complete if the recipient received an intended blood group incompatible donor heart, lung, or heart/lung.

Most Recent Anti-A Titer: Select the Most Recent Anti-A Titer value, Not taken or Not available if applicable. Enter the **Sample Date** in mm/dd/yyyy format. The date to be reported is the date when the candidate's blood was drawn.

**Note:** The **Sample Date** cannot be greater than 30 days prior to transplant date, cannot be prior to the candidate's date of birth, cannot be a future date and cannot be after the transplant date. This field will only display if the recipient's ABO blood-type is B or O.

Most Recent Anti-B Titer: Select the Most Recent Anti-B Titer value, Not taken or Not available if applicable. Enter the Sample Date in mm/dd/yyyy format. The date to be reported is the date when the candidate's blood was drawn.

**Note:** The **Sample Date** cannot be greater than 30 days prior to transplant date, cannot be prior to the candidate's date of birth, cannot be a future date and cannot be after the transplant date. This field will only display if the recipient's ABO blood-type is A or O.

#### **Clinical Information: TRANSPLANT PROCEDURE**

<u>Multiple Organ Recipient</u>: 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.

<u>Were extra vessels used in the transplant procedure</u>: 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. Donor IDs entered for this question must be from deceased donors. All deceased donor extra vessels must be monitored due to the potential for disease transmission.

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

<u>Procedure Type</u>: The procedure type, reported on the Recipient Feedback, will display. Verify the information displayed in the Procedure Type field is correct.

## Heart

**Heart Lung** 

**Procedure Information** (Heart Only): For heart recipients, select the appropriate procedure information. This field is **required**.

Orthotopic Bicaval: Superior and inferior venacaval anastomoses.

**Orthotopic Traditional:** Right and left atrial anastomoses.

Orthotopic Total (Bicaval, PV): Orthotopic bicaval anastomoses plus pulmonary vein anastomosis.

**Heterotopic:** The recipient's native heart was not removed.

## **Procedure Information (Heart/Lung):**

The recipient received an en-bloc heart lung transplant.

#### **Procedure Information (Lung Only):**

Single Left Lung: The recipient received a single left lung.

**Single Right Lung:** The recipient received a single right lung.

**Bilateral Sequential Lung:** The recipient received both lungs from a single donor, which were transplanted sequentially. Ischemic times should be reported for both lungs.

**En-Block Double Lung:** The recipient received both lungs from the same donor, which were transplanted en-bloc or together. One Ischemic times should be reported for both lungs.

**Lobe**, **Right**: The recipient received a single right lobe.

**Lobe**, **Left**: The recipient received a single left lobe.

## **Ex Vivo Lung Perfusion (EVLP)**

<u>Total organ preservation time from cross clamp to in-situ reperfusion (include warm and cold time)</u>: Enter the total ischemia time, for the right lung, left lung, or en-bloc lungs, in minutes. If the time is unavailable, select the status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**).

**Lung(s) perfused prior to transplant**: If the lung(s) was perfused prior to transplant select yes. If not, select **No**. If **Yes** is selected, then answer the following:

Perfusion occurred at (Select one of the following perfusion sites):

Recovery site (donor hospital)

OPO

Transplant hospital - transplant site

Transplant hospital - not transplant site

**External perfusion center** 

Perfusion performed by (Select which institution performed the perfusion):

**OPO** 

**Transplant program** 

**External perfusion center** 

**Total time on perfusion (minutes):** Enter the total time that the lung(s) underwent perfusion.

#### Lung(s) received at transplant center :

**On Ice:** If the transplant center received the lung(s) on ice select **Yes**. If the lungs were not on ice enter **No.** If **No** is selected, provide the following information:

**On Pump:** If the transplant center received the lung(s) on a pump select **Yes**. If the lungs were not on a pump enter **No.** If **Yes** is selected, provide the following information (Note\*\* Only lungs transplanted will be displayed):

#### 1. Right lung/En-bloc

- a. **Stayed on pump** select if the lung remained on the pump for perfusion
- b. **Put on ice** select if the lung was removed from the pump and put on ice.

## 2. Left lung

- a. **Stayed on pump** select if the lung remained on the pump for perfusion
- b. **Put on ice** select if the lung was removed from the pump and put on ice.

#### **Clinical Information: POST TRANSPLANT**

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

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

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

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

**Primary Cause of Graft Failure:** Select the cause of graft failure.

Primary Non-Function Acute Rejection Chronic Rejection/Atherosclerosis Other, Specify

<u>Post Transplant Titer Information</u>: Complete if the recipient received an intended blood group incompatible donor heart, lung, or heart/lung and death or graft failure is reported on the TRR:

Most Recent Anti-A Titer: Select the Most Recent Anti-A Titer value, Not taken or Not available if applicable. Enter the Sample Date in mm/dd/yyyy format. The date to be reported is the date when the candidate's blood was drawn.

**Note:** The **Sample Date** cannot be prior to the recipient's transplant date, cannot be after the graft failure or the death date and cannot be a future date. This field will only display if the recipient's ABO blood-type is B or O.

Most Recent Anti-B Titer: Select the Most Recent Anti-B Titer value, Not taken or Not available if applicable. Enter the **Sample Date** in mm/dd/yyyy format. The date to be reported is the date when the candidate's blood was drawn.

**Note:** The **Sample Date** cannot be prior to the recipient's transplant date, cannot be after the graft failure or the death date and cannot be a future date. This field will only display if the recipient's ABO blood-type is A or O.

#### **Events Prior to Discharge:**

For each of the events listed indicate if the event occurred during the post-transplant hospital course prior to discharge.

**Stroke:** If the recipient experienced a stroke (CVA) following the transplant, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

**Dialysis:** If the recipient needed to have peritoneal or hemodialysis following the transplant, select **Yes.** If not, select **No.** If unknown, select **UNK**. This field is **required**.

**Ventilator support** (Lung and Heart/Lung Only): If recipient <u>did not</u> receive ventilator support, select **No**. If the recipient <u>received</u> ventilator support, select the duration. If ventilator support status is unknown, select **Unknown Status**. If the recipient received ventilator support, indicate the duration of the their ventilator support. If the duration is unknown, select **Ventilator support**, **duration unknown**. This field is **required** 

Ventilator support for <= 48 hours Ventilator support for > 48 hours but < 5 days Ventilator support >= 5 days Ventilator support, duration unknown Unknown Status

**Reintubated** (Lung and Heart/Lung Only): If the recipient was reintubated, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

**Permanent Pacemaker:** If the recipient needed a permanent pacemaker implantation during the initial hospitalization following the transplant operation, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

**Airway Dehiscence:** If the recipient developed an airway dehiscence during the initial hospitalization following the transplant operation, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

## Components of ISHLT primary graft dysfunction (PGD) grade:

Intubated at 72 hours: If not, select NO. If unknown, select UNK.

Pa02 at 72 hours: Either the actual value or the status field must be provided. Missing, Unknown, N/A, Not Done

**Fi02 at 72 hours:** Either the actual value or the status field must be provided. **Missing, Unknown, N/A, Not Done**. If a recipient has been extubated prior to 72 hours, please enter N/A.

ECMO at 72 hours: If not, select NO. If unknown, select UNK.

Inhaled NO at 72 hours: If not, select NO. If unknown, select UNK.

<u>Did patient have any acute rejection episodes between transplant and discharge</u>: 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. This field is **required**.

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

#### **Immunosuppressive Information**

<u>Are any medications given currently for maintenance or anti-rejection</u>: 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. This field is **required**.

#### **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 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 (**Missing**, **Unknown**, **N/A**, **Not Done**).

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

Select the appropriate status from the applicable **Status** field (**Missing, Unknown, N/A, Not Done**).

Steroids (prednisone, methylprednisolone, Solumedrol, Medrol, Decadron)

## Drugs used for induction or acute rejection

Select the appropriate status from the applicable **Status** field (**Missing, Unknown, N/A, Not Done**).

**Atgam** 

Campath (alemtuzumab, anti-CD52)

Cytoxan (cyclophosphamide)

Methotrexate (Folex PFS, Mexate-AQ, Rheumatrex)

OKT3 (Orthoclone, muromonab)

Rituxan (rituximab)

Simulect (basiliximab)

Thymoglobulin

## Drugs primarily used for maintenance

Select the appropriate status from the applicable **Status** field (**Missing, Unknown, N/A, Not Done**).

#### Cyclosporine, select from the following:

- EON (generic cyclosporine)
- Gengraf (Abbott cyclosporine)
- Neoral (CyA-NOF)
- Other generic cyclosporine, specify brand:
- Sandimmune (cyclosporine A)

- Imuran (azathioprine, AZA)
- Leflunomide (LFL)

## Mycophenolate acid, select from the following:

- CellCept (MMF)
- Generic MMF (generic CellCept)
- Myfortic (mycophenolate acid)
- Nulojix (belatacept)
- Rapamune (sirolimus, Rapamycin)

## Tacrolimus, select from the following:

- Astagraf XL (extended release tacrolimus)
- Generic tacrolimus (generic Prograf)
- Prograf (FK506)
- Zortress (everolimus)

## Other drugs

Select the appropriate status from the applicable **Status** field (**Missing, Unknown, N/A, Not Done**). Other immunosuppressive medication, specify: