Heart/Lung Transplant Candidate Registration (TCR) Record Field Descriptions

The Transplant Candidate Registration (TCR) record is generated when a candidate for transplant is added to the OPTN/UNOS waiting list. A TCR will also be generated in the case of a living donor transplant, where the recipient was not added to the WaitlistSM, and was added through the living donor feedback process.

If the candidate is already on the waiting list for a transplant, another TCR record will not be generated unless listed by a different center or for another organ type.

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

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

Provider Information

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

Candidate Information

<u>Organ Registered</u>: Verify the organ(s) displayed is/are the organ(s) listed for this candidate. If the candidate is listed for more than one type of transplant, both organs should be displayed. Separate records exist for certain multi-organ transplant candidates (e.g. Heart/Lung and Kidney/Pancreas).

Date of Listing or Add: The date the candidate was listed or added in Waitlist will display.

<u>Name</u>: The waitlisted candidate's last name, first name and middle initial will be displayed. If it is incorrect, corrections must be completed on the active waitlist. For a candidate who has been removed from the waitlist, the **Last Name**, **First Name** and **MI** fields will display. Corrections may be made directly in the record. These fields are **required**.

<u>Previous Surname</u>: If the candidate had a previous surname that is different from the Name entered, enter the previous surname.

<u>SSN</u>: Verify the candidate's social security number. If the information is incorrect and the candidate is waitlisted, contact the UNOS Organ Center at 1-800-292-9537.

<u>Gender</u>: Verify candidate's gender. If the gender is not displayed or is incorrect and the candidate is on the active waitlist, correction must be completed on the active waitlist record. If the candidate has been removed from the active waitlist, corrections may be made directly in the record. This field is **required**.

HIC: Enter the 9 to 11 character Health Insurance Claim number for the candidate. If the candidate does not have a HIC number, you may leave this field blank.

<u>DOB</u>: Verify the displayed date is the candidate's date of birth. If the information is incorrect, correction must be completed on the active waitlist. If the candidate has been removed, reenter the correct date using the 8-digit numeric format of MM/DD/YYYY. Corrections may be made directly in the record. This field is **required**.

<u>State of Permanent Residence</u>: Select the name of the state of the candidate's permanent address at the time of listing (location of full-time residence, not where the candidate is currently waiting). This field is **required**. (**List of State codes – See <u>Appendix A</u>**)

<u>Permanent Zip Code</u>: Enter the candidate's permanent zip code (location of full-time residence, not where the candidate is currently waiting). This field is **required**.

Ethnicity/Race: Select all origins that indicate the candidate's ethnicity/race. This field is **required**

American Indian or Alaska Native: Select for candidates who are of North, South, or Central American descent (e.g. American Indian, Eskimo, Aleutian, Alaska Indian). If the candidate belongs to the primary category, but does not belong to any of the subcategories listed, select American Indian or Alaska Native: Other. If unknown, select American Indian or Alaska Native: Not Specified/Unknown.

Asian: Select for candidates who are of Asian descent (e.g. Asian Indian/Indian Sub-Continent, Chinese, Filipino, Japanese, Korean, Vietnamese). If the candidate belongs to the primary category, but does not belong to any of the subcategories listed, select Asian: Other. If unknown, select Asian: Not Specified/Unknown.

Black or African American: Select for candidates of African descent (e.g. African American, African (Continental), West Indian, Haitian). If the candidate belongs to the primary category, but does not belong to any of the subcategories listed, select Black or African American: Other. If unknown, select Black or African American: Not Specified/Unknown.

Hispanic/Latino: Select for candidates who are of Central or South American descent (e.g. **Mexican, Puerto Rican (Mainland), Puerto Rican (Island), Cuban)**. If the candidate belongs to the primary category, but does not belong to any of the subcategories listed, select **Hispanic/Latino: Other**. If unknown, select **Hispanic/Latino: Not Specified/Unknown**.

Native Hawaiian or Other Pacific Islander: Select for candidates who are descendants of the Native Hawaiian, Guamanian or Chamorro, or Samoan peoples. If the candidate belongs to the primary category, but does not belong to any of the subcategories listed, select Native Hawaiian or Other Pacific Islander: Other. If unknown, select Native Hawaiian or Other Pacific Islander: Not Specified/Unknown.

White: Select for candidates who are of European Descent, Arab or Middle Eastern or North African (non-Black). If the candidate belongs to the primary category, but does not belong to any of the subcategories listed, select White: Other. If unknown, select White: Not Specified/Unknown.

Citizenship: Select as appropriate to indicate the candidate's citizenship. This field is required.

U.S. Citizen: A United States citizen by birth or naturalization.

Non-U.S. Citizen/U.S. Resident: A non-citizen of the United States for whom the United States is the primary place of residence.

Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Reason Other Than Transplant: A non-citizen of the United States for whom the United States is not the primary place of residence, and who came to the U.S. for a reason other than transplant.

Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Transplant: A non-citizen of the United States for whom the United States is not the primary place of residence, and who came to the U.S. for the purpose of transplant.

Country of Permanent Residence: If Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Reason Other Than Transplant or_Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Transplant is selected, enter the country associated with the primary place of residence. This field is required.

Year of Entry to the U.S.: If the candidate is a Non-U.S. Citizen/Non-U.S. Resident, enter the year the candidate entered the United States. If unknown, select **UNK**. This field is **required**.

<u>Highest Education Level</u>: Select the choice which best describes the candidate's highest level of education. This field is **required**.

None
Grade School (0-8)
High School (9-12) or GED
Attended College/Technical School
Associate/Bachelor Degree
Post-College Graduate Degree
N/A (< 5 Yrs Old)
Unknown

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

Extra Corporeal Membrane Oxygenation

Intra Aortic Balloon Pump

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

Prostacyclin Infusion

Prostacyclin Inhalation

Inhaled NO

IV Inotropes (pediatric candidates only)

Other Mechanism, Specify

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

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

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

Maquet Josta Rotaflow

Medos

MicroMed DeBakey

MicroMed DeBakey - Child

PediMag (Thoratec/Levitronix)

Terumo DuraHeart

Thoratec IVAD

Thoratec PVAD

Toyobo

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: (See Above)

<u>Functional Status:</u> Select the choice that best describes the candidate's functional status at the time of listing. This field is **required**.

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

100% - Normal, no complaints, no evidence of disease

90% - Able to carry on normal activity: minor symptoms of disease

80% - Normal activity with effort: some symptoms of disease

70% - Cares for self: unable to carry on normal activity or active work

60% - Requires occasional assistance but is able to care for needs

50% - Requires considerable assistance and frequent medical care

40% - Disabled: requires special care and assistance

30% - Severely disabled: hospitalization is indicated, death not imminent

20% - Very sick, hospitalization necessary: active treatment necessary

10% - Moribund, fatal processes progressing rapidly

Unknown

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

100% - Fully active, normal

90% - Minor restrictions in physically strenuous activity

80% - Active, but tires more quickly

70% - Both greater restriction of and less time spent in play activity

60% - Up and around, but minimal active play; keeps busy with quieter activities

50% - Can dress but lies around much of day; no active play; can take part in quiet

play/activities

40% - Mostly in bed; participates in guiet 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>: (Complete for candidates 18 years of age or younger.) Select the choice that best describes the candidate'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 candidates 18 years of age or younger.) Select the choice that best describes the candidate'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

<u>Working for income</u>: (Complete for candidates years of age or older.) If the candidate is working for income, select **Yes**. If not, select **No**. If unknown, select **UNK**.

<u>Academic Progress</u>: (This field is required for candidates less than 18 years of age.) Select the choice that best describes the candidate's academic progress at the time of listing. If the candidate 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 candidates less than 18 years of age.) Select the choice that best describes the candidate's academic activity level at the time of listing. If the candidate 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>Previous Transplants</u>: The three most recent transplant(s), indicated on the candidate'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 candidate 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 <u>unethelpdesk@unos.org</u> to determine if the transplant event is in the database.

Source of Payment:

Primary: Select as appropriate to indicate the candidate's source of primary payment (largest contributor) for the transplant. If the source of payment is not yet determined, select **Pending**. 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 candidate. 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 candidate, along with additional benefits such as coordination of care or reducing-out-of-pocket expenses. Sometimes a candidate 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 refers to funds from another government agency.

Self indicates that the candidate 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 candidate.

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

Pending is used if the source of payment is not yet determined (Primary only).

Foreign Government, Specify refers to funds provided by a foreign government (Primary only) Specify the foreign country in the space provided. (<u>List of Foreign Country codes – See Appendix E</u>)

Clinical Information: At Listing

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

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

<u>Weight</u>: Enter the weight of the candidate at the time of listing in the appropriate space, in pounds or kilograms. If the candidate's weight is unavailable, select the appropriate status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**). This field is **required**. For candidates 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 candidate's BMI will display. For candidates less than 20 years of age at the time of listing, UNetSM 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 http://www.cdc.gov/.

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

ABO Blood Group: The candidate's blood type will be displayed. If the blood type is incorrect, correction must be completed on the active waitlist. If the candidate has been removed from the active waitlist, you may select the candidate's correct blood type directly in the record.

A
A1
A1B
A2
A2B
AB
B
O
Z (In Utero Only)

<u>Primary Diagnosis</u>: Select the primary diagnosis for the disease requiring a transplant at the time of listing for this candidate. If the candidate has had a previous transplant for the same organ type, use Retransplant/Graft Failure as the primary diagnosis for that organ. If an Other code is selected, use the blank provided to specify the Other diagnosis. This field is required. (List of Thoracic Diagnosis codes – See Appendix F)

<u>General Medical Factors</u>: For each of the medical factors listed, select the appropriate responses to indicate if the candidate has a history of the factor prior to listing.

Diabetes: If the candidate does not have a history of diabetes, select **No**. If the candidate has diabetes, select **Type I** or **Type II**. If the candidate has any type of induced diabetes, select **Type Other**. If the candidate has a history of diabetes but the type is unknown, select **Type Unknown**. If this information is unknown, select **Diabetes Status Unknown**. This field is **required**.

No

Type I is defined as a disease in which the body does not produce any insulin, most often occurring in children and young adults. People with Type 1 diabetes must take daily insulin injections to stay alive. Type 1 diabetes accounts for 5 to 10 percent of diabetes. **Type II** is defined as a metabolic disorder resulting from the body's inability to make enough, or

properly use, insulin. It is the most common form of the disease. Type 2 Diabetes accounts for 90 to 95 percent of diabetes.

Type Other
Type Unknown

Diabetes Status Unknown

Any previous malignancy: If the candidate currently has malignant cancer or has a history of any previous malignant cancer, select **Yes**. If the candidate does not currently have malignant cancer and has not had a history of any previous malignant cancer, select **No**. If **Yes** is selected, select the type(s) of malignancy. If **Other, specify** is selected, indicate the type of tumor in the space provided. This field is **required**.

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

Total Serum Albumin: Enter the total serum albumin value in g/dl. If the value is unavailable, select the appropriate status from the **ST** field (**Missing**, **Unknown**, N/A, **Not Done**). This field is **required** for candidates less than 18 years of age.

Heart Medical Factors

<u>Sudden Death</u>: If the candidate has experienced any episodes of sudden death (cardiac arrest with resuscitation) prior to the time of listing, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required** for candidates less than 18 years of age.

<u>Implantable Defibrillator</u>: If the candidate had an implantable defibrillator at the time of listing, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

<u>Exercise Oxygen Consumption</u>: Enter the candidate's oxygen consumption at exercise in ml/min/kg. If the value is unavailable, select the appropriate status from the **ST** field (**Missing**, **Unknown**, **N/A**, **Not Done**). This field is **required**.

Lung Medical Factors

<u>Pan-Resistant Bacterial Lung Infection</u>: If the candidate has a history of pan-resistant bacterial lung infection prior to listing, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

Heart/Lung Medical Factors

<u>Most recent Hemodynamics</u>: Enter the most recent hemodynamic values. For each measure, indicate if the measurement was obtained while the candidate 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**.

<u>History of Cigarette Use</u>: If the candidate has a history of cigarette use, select **Yes**. If not, select **No**.. Then indicate the **Duration of Abstinence**. This field is **required**.

Duration of Abstinence: Select the number of months the candidate has abstained from cigarettes. If the time is unknown, select **Unknown duration**. If the candidate has not stopped smoking, select **Continues To Smoke**. This field is **required**.

0-2 months

3-12 months

13-24 months

25-36 months

37-48 months

49-60 months

>60 months

Continues to Smoke

Unknown duration

[ADULT CANDIDATES]

Prior Cardiac Surgery (non-transplant): If the candidate had cardiac surgery prior to listing, select **Yes.** If no prior cardiac surgery, select **No.** 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

[PEDIATRIC CANDIDATES]

Prior Thoracic Surgery Other Than Prior Transplant: If the candidate 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. This field is **required**.

If yes, number of prior sternotomies (List of Sternotomies codes - See Appendix G)

If yes, number of prior thoracotomies (List of Thoracotomies codes – See Appendix H)

<u>Prior Congenital Cardiac Surgery</u>: If the candidate 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.