Pancreas and Pancreas Islets 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 candidate was not added to the Waitlist[™], 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 <u>OPTN Policy</u> 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.

The Pancreas and Pancreas Islet fields are the same.

Provider Information

<u>Recipient</u> <u>Center</u>: 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**.

Previous Surname: 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**.

<u>HIC</u>: 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.

DOB: 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: This field will display and be required if the recipient's citizenship is one of the two values of 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. 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>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 quiet activities
30% - In bed; needs assistance even for quiet play
20% - Often sleeping; play entirely limited to very passive activities
10% - No play; does not get out of bed
Not Applicable (patient < 1 year old)
Unknown

Note: This evaluation should be in comparison to the person's normal function, indicating how the patient's disease has affected their normal function.

<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

Working for income: (Complete for candidates 19 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.

Previous Pancreas Islet Infusion: If the candidate received a previous pancreas islet infusion, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required** for candidates 18 years of age and older.

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 <u>additional benefits</u> 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. (List of Foreign Country codes – See <u>Appendix E</u>)

Clinical Information: At Listing

Date of Measurement: (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.

Weight: 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.

<u>BMI (Body Mass Index)</u>: The candidate's BMI will display. For candidates less than 20 years of age 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/.

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 UNetsm using 4 decimal places for weight and 2 for height.

<u>ABO Blood Group</u>: 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 Pancreas Diagnosis codes – See <u>Appendix O</u>)

<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

Symptomatic Peripheral Vascular Disease: If the candidate is experiencing or has a history of intermittent claudication, diminished peripheral pulses or other signs and symptoms of peripheral vascular disease at the time of listing, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required** for candidates 18 years of age and older.

Drug Treated COPD: If the candidate is currently or has a history of taking any medication to control signs and symptoms of COPD (Chronic Obstructive Pulmonary Disease) at the time of listing, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required** for adults.

Any previous malignancy: 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

Most Recent Serum Creatinine: Enter the most recent serum creatinine value in mg/dl. If the value is unavailable, select the appropriate status from the ST field (Missing, Unknown, N/A, Not Done).

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.

Pancreas Medical Factors

<u>Age of Diabetes Onset</u>: If diabetes is indicated in the *General Medical Factors*, enter the age of diabetes onset in years in the space provided. If the value is unavailable, select the appropriate status from the **ST field (Missing, Unknown, N/A, Not Done)**. This field is **required**.