

Pediatric Thoracic Transplant Recipient Follow-Up Worksheet

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI® application. Currently in the worksheet, a red asterisk is displayed by fields that are required, independent of what other data may be provided. Based on data provided through the online TIEDI® application, additional fields that are dependent on responses provided in these required fields may become required as well. However, since those fields are not required in every case, they are not marked with a red asterisk.

Recipient Information	
Name:	DOB:
SSN:	Gender:
HIC:	Tx Date:
Previous Follow-Up:	Previous Px Stat Date:
Transplant Discharge Date:	<input type="text"/>
State of Permanent Residence: *	<input type="text"/>
Zip Code: *	<input type="text"/> - <input type="text"/>

Provider Information	
Recipient Center:	
Followup Center:	
Physician Name: *	<input type="text"/>
NPI#: *	<input type="text"/>
Follow-up Care Provided By: *	<input type="radio"/> Transplant Center <input type="radio"/> Non Transplant Center Specialty Physician <input type="radio"/> Primary Care Physician <input type="radio"/> Other Specify
Specify:	<input type="text"/>

Donor Information	
UNOS Donor ID #:	
Recovering OPO:	
Donor Type:	

Patient Status	
Date: Last Seen, Retransplanted or Death: *	<input type="text"/>
Patient Status: *	<input type="radio"/> LIVING <input type="radio"/> DEAD <input type="radio"/> RETRANSPLANTED <input type="radio"/> NOT SEEN
Primary Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Has the patient been hospitalized since the last patient status date: *	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Hospitalized for Rejection:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Hospitalized for Infection:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Functional Status: *	<input type="text"/>

Cognitive Development: *	<input type="radio"/> Definite Cognitive delay/impairment <input type="radio"/> Probable Cognitive delay/impairment <input type="radio"/> Questionable Cognitive delay/impairment <input type="radio"/> No Cognitive delay/impairment <input type="radio"/> Not Assessed
Motor Development: *	<input type="radio"/> Definite Motor delay/impairment <input type="radio"/> Probable Motor delay/impairment <input type="radio"/> Questionable Motor delay/impairment <input type="radio"/> No Motor delay/impairment <input type="radio"/> Not Assessed
Academic Progress: *	<input type="radio"/> Within One Grade Level of Peers <input type="radio"/> Delayed Grade Level <input type="radio"/> Special Education <input type="radio"/> Not Applicable, too young for school/ High School graduate or GED <input type="radio"/> Status Unknown
Academic Activity Level: *	<input type="radio"/> Full academic load <input type="radio"/> Reduced academic load <input type="radio"/> Unable to participate in academics due to disease or condition <input type="radio"/> Unable to participate regularly due to dialysis <input type="radio"/> Not Applicable, too young for school/ High School graduate or GED <input type="radio"/> Status Unknown
Primary Insurance at Follow-up: *	<input type="text"/>
Specify	<input type="text"/>

Clinical Information			
Height Measurement Date:	<input type="text"/>		
Height: *	<input type="text"/> ft. <input type="text"/> in.	<input type="text"/> cm	ST= <input type="text"/>
Weight Measurement Date:	<input type="text"/>		
Weight: *	<input type="text"/> lbs.	<input type="text"/> kg	ST= <input type="text"/>
BMI:	<input type="text"/> kg/m ²		
Graft Status: *	<input type="radio"/> Functioning <input type="radio"/> Failed		
<p>If death is indicated for the recipient, and the death was a result of some other factor unrelated to graft failure, select Functioning.</p>			
Date of Graft Failure:	<input type="text"/>		
Primary Cause of Graft Failure:	<input type="radio"/> Primary Non-Function <input type="radio"/> Acute Rejection <input type="radio"/> Chronic Rejection/Atherosclerosis <input type="radio"/> Other, Specify		
Other, Specify:	<input type="text"/>		
Titer Information:			
<p>For those individuals who received a heart and/or lung from a donor with an incompatible blood type, the most recent Anti-A and/or Anti-B titer values must be reported upon graft failure or death.</p>			
Titer values entered on the TRR:			
Anti-A Titer at time of transplant:	<input type="text"/>	Sample Date:	<input type="text"/>
Most Recent Anti-A Titer: *	<input type="text"/>	Sample Date: *	<input type="text"/>
Titer values entered on the TRR:			
Anti-B Titer at time of transplant:	<input type="text"/>	Sample Date:	<input type="text"/>
Most Recent Anti-B Titer: *	<input type="text"/>	Sample Date: *	<input type="text"/>
Graft Function:			

Heart:

Ejection Fraction:* % **ST=**

Shortening Fraction:* % **ST=**

Pacemaker:* YES NO UNK

Coronary Artery Disease Since Last Follow Up:* YES NO UNK

Post Transplant Events:

New diabetes onset between last follow-up to the current follow-up:* YES NO UNK

If yes, insulin dependent: YES NO UNK

Most Recent Serum Creatinine:* mg/dl **ST=**

Chronic Dialysis:* YES NO UNK

Renal Tx since Thoracic Tx:* YES NO UNK

Did patient have any acute rejection episodes during the follow-up period:* Yes, at least one episode treated with anti-rejection agent
 Yes, none treated with additional anti-rejection agent
 No
 Unknown

Viral Detection:

HIV Serology	<input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> UKN/ Cannot Disclose <input type="radio"/> Not Done
HIV NAT	<input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> UKN/ Cannot Disclose <input type="radio"/> Not Done
HbsAg	<input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> UKN/ Cannot Disclose <input type="radio"/> Not Done
HBV DNA	<input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> UKN/ Cannot Disclose <input type="radio"/> Not Done
HBV Core Antibody	<input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> UKN/ Cannot Disclose <input type="radio"/> Not Done
HCV Serology	<input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> UKN/ Cannot Disclose <input type="radio"/> Not Done
HCV NAT	<input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> UKN/ Cannot Disclose <input type="radio"/> Not Done
Post Transplant Malignancy:*	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Donor Related:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Recurrence of Pre-Tx Tumor:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
De Novo Solid Tumor:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
De Novo Lymphoproliferative disease and Lymphoma:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK

Immunosuppressive Information	
Previous Validated Maintenance Follow-Up Medications:	
Previous Validated Maintenance Follow-Up Medications:	
Were any medications given during the follow-up period for maintenance:	<input type="radio"/> Yes, same as validated TRR form <input type="radio"/> None given <input type="radio"/> Yes, but different than validated TRR form

Immunosuppressive Medications

View Immunosuppressive Medications

Definitions Of Immunosuppressive Follow-Up Medications

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

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

Current Maintenance (Curr Maint) includes all immunosuppressive medications given at the time of the current clinic visit to begin in the next report period, with the intention to maintain them long-term (example: prednisone, cyclosporine, tacrolimus, mycophenolate mofetil, azathioprine, or Rapamune). This does not include any immunosuppressive medications given to treat rejection episodes.

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

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

Drug used for induction, acute rejection, or maintenance

	Prev Maint	Curr Maint	AR
Steroids (prednisone, methylprednisolone, Solumedrol, Medrol)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Drugs used for induction or acute rejection

	Prev Maint	Curr Maint	AR
Atgam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Campath (alemtuzumab)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cytoxan (cyclophosphamide)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Methotrexate (Folex PFS, Mexate-AQ, Rheumatrex)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rituxan (rituximab)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Simulect (basiliximab)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thymoglobulin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Drugs primarily used for maintenance

	Prev Maint	Curr Maint	AR
Cyclosporine, select from the following:			
- Gengraf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Neoral	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Sandimmune	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic cyclosporine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Imuran (azathioprine, AZA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mycophenolic acid, select from the following:			
- CellCept (MMF)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic MMF (generic CellCept)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Myfortic (mycophenolic acid)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic Myfortic (generic mycophenolic acid)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
mTOR inhibitors, select from the following:			
- Rapamune (sirolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic sirolimus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Zortress (everolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nulojix (belatacept)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tacrolimus, select from the following:			
- Astagraf XL (extended release tacrolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Envarsus XR (tacrolimus XR)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Prograf (tacrolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic tacrolimus (generic Prograf)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other drugs

		Prev Maint	Curr Maint	AR
Other immunosuppressive medication, specify:	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other immunosuppressive medication, specify:	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>