

Records ?

Pediatric Kidney-Pancreas Transplant Recipient Follow-Up Worksheet

The revised worksheet sample is for reference purposes only and is pending OMB approval.

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI^B 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^B 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 #:	
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
If Retransplanted, choose organ(s):	<input type="radio"/> Kidney <input type="radio"/> Pancreas <input type="radio"/> Kidney/Pancreas
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"/>
Hospitalizations:	
Has the patient been hospitalized since the last patient status date: *	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Number of Hospitalizations:	<input type="text"/> St= <input type="text"/>
Noncompliance:	
Was there evidence of noncompliance with immunosuppression medication during this follow-up period that compromised the patient's recovery:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Functional Status: *	<input type="text"/>
	<input type="radio"/> Definite Cognitive delay/impairment (verified by IQ score <70 or unambiguous behavioral observation)

Cognitive Development: *

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: *

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 indications of motor delay/impairment)
 No Motor delay/impairment (no obvious indicators of motor delay/impairment)
 Not Assessed

Academic Progress: *

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

Academic Activity Level: *

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

Primary Insurance at Follow-up: *

Specify:

Clinical Information

Date of Measurement: *

Height: * ft. in. cm %ile **St=**
Weight: * lbs. kg %ile **St=**
BMI: kg/m² %ile

Is growth hormone therapy used during this follow-up period: * YES NO UNK

Urine Protein Found By Any Method: YES NO UNK

Bone Disease: *

Fracture in the past year (or since last follow-up): YES NO UNK

Specify Location and number of fractures:

Spine-compression fracture # of fractures:
 Extremity # of fractures:
 Other # of fractures:

AVN (avascular necrosis): YES NO UNK

Kidney Graft Status: * Functioning Failed

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

If Functioning, Most Recent Serum Creatinine: mg/dl **St=**

Kidney Date of Failure:

Kidney Primary Cause of Graft Failure:

Specify

Contributory causes of graft failure:

- Kidney Acute Rejection YES NO UNK
- Kidney Chronic Rejection YES NO UNK
- Kidney Graft Thrombosis YES NO UNK
- Kidney Infection YES NO UNK
- Urological Complications YES NO UNK
- Patient Noncompliance YES NO UNK
- Recurrent Disease: YES NO UNK
- BK (Polyoma) Virus YES NO UNK
- Kidney Other Contributory Cause of Graft Failure

- Dialysis Since Last Follow-Up: NO
 YES, RESUMED MAINTENANCE DIALYSIS
 YES, NO MAINTENANCE RESUMPTION
 YES, MAINTENANCE RESUMPTION UNKNOWN
 UNKNOWN
- Date Maintenance Dialysis Resumed:
- Select a Dialysis Provider:
- Provider #:
- Provider Name:

Pancreas Graft Status:* Functioning Partial Function Failed

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

- Method of blood sugar control: Insulin
 Oral medication
 Diet
 No Treatment
- Date insulin/medication resumed:
- Pancreas Date of Failure
- Pancreas Graft Removed: YES NO UNK
- Date Pancreas Removed:
- Pancreas Primary Causes of Graft Failure
- Specify:
- Contributory causes of graft failure:
- Pancreas Graft/Vascular Thrombosis YES NO UNK
 - Pancreas Infection YES NO UNK
 - Pancreas Bleeding YES NO UNK
 - Anastomotic Leak YES NO UNK
 - Pancreas Rejection: Acute YES NO UNK
 - Pancreas Chronic Rejection YES NO UNK
 - Biopsy Proven Isletitis YES NO UNK
 - Pancreatitis YES NO UNK
 - Patient Noncompliance YES NO UNK
 - Other, Specify:

Conv. From Bladder to Enteric Drain Performed:* YES NO UNK

Enteric Drain Date:

Serum Amylase: u/L St=

Pancreas Transplant Complications (Not leading to graft failure):

Pancreatitis* YES NO UNK

Anastomotic Leak* YES NO UNK

Abcess or Local Infection* YES NO UNK

Other, Specify:

Did patient have any kidney 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
- Biopsy not done
- Yes, rejection confirmed
- Yes, rejection not confirmed
- Unknown

Was biopsy done to confirm acute rejection:

Did patient have any pancreas 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
- Biopsy not done
- Yes, rejection confirmed
- Yes, rejection not confirmed
- Unknown

Was biopsy done to confirm acute rejection:

CMV IgG:*

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

CMV IgM:*

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

Postransplant Malignancy:* YES NO UNK

Donor Related: YES NO UNK

Recurrence of Pre-Tx Tumor: YES NO UNK

De Novo Solid Tumor: YES NO UNK

De Novo Lymphoproliferative disease and Lymphoma: YES NO UNK

Treatment

Biological or Anti-viral therapy: YES NO Unknown/Cannot disclose

Acyclovir (Zovirax)

If Yes, check all that apply:

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

Specify:

Specify:

Treatment for BK (polyoma) virus:

YES NO

If Yes, check all that apply:

- Yes, Immunosuppression reduction
- Yes, Cidofovir
- Yes, IVIG
- Yes, Type Unknown
- Yes, Other, Specify

Specify:

Other therapies:

YES NO

If Yes, check all that apply:

- Photopheresis
- Plasmapheresis
- Total Lymphoid Irradiation (TLI)

Immunosuppressive Information

Previous Validated Maintenance Follow-Up Medications:

Were any medications given during the follow-up period for maintenance: *

Yes, same as previous validated report

Yes, but different than previous validated report

None given

Did the physician discontinue all maintenance immunosuppressive medications:

YES NO

Did the patient participate in any clinical research protocol for immunosuppressive medications:

YES NO

Specify:

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, *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* (example: Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). This does not include any immunosuppressive medications given to treat rejection episodes.

Current Maintenance (Curr Maint) includes all immunosuppressive medications given at the current clinic visit to begin in the next report *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* (example: Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). 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, Atgam, OKT3, 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.**

Prev Maint Curr Maint AR

Steroids (Prednisone, Methylprednisolone, Solumedrol, Medrol, Decadron)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Atgam (ATG)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
OKT3 (Orthoclone, Muromonab)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Thymoglobulin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Simulect - Basiliximab	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Zenapax - Daclizumab	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Azathioprine (AZA, Imuran)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
EON (Generic Cyclosporine)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Gengraf (Abbott Cyclosporine)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other generic Cyclosporine, specify brand: <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Neoral (CyA-NOF)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sandimmune (Cyclosporine A)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Mycophenolate Mofetil (MMF, Cellcept, RS61443)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Tacrolimus (Prograf, FK506)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Modified Release Tacrolimus FK506E (MR4)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sirolimus (RAPA, Rapamycin, Rapamune)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Myfortic (Mycophenolate Sodium)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Other Immunosuppressive Medications			
	Prev Maint	Curr Maint	AR
Campath - Alemtuzumab (anti-CD52)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Cyclophosphamide (Cytoxan)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL, Arava)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
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"/>
Rituximab	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Investigational Immunosuppressive Medications			
	Prev Maint	Curr Maint	AR
Everolimus (RAD, Certican)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
FTY 720	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>