

Records

Pediatric Kidney 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
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"/>
TRR Diagnosis:	Disease Recurrence: <input type="radio"/> No recurrence <input type="radio"/> Suspected recurrence (not confirmed or unknown is confirmed by biopsy) <input type="radio"/> Biopsy confirmed recurrence <input type="radio"/> Unknown
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 style="width: 100%;" type="text"/>
Cognitive Development: *	<input type="radio"/> Definite Cognitive delay/impairment (verified by IQ score <70 or unambiguous behavioral observation) <input type="radio"/> Probable Cognitive delay/impairment (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence) <input type="radio"/> 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) <input type="radio"/> No Cognitive delay/impairment (no obvious indicators of cognitive delay/impairment) <input type="radio"/> Not Assessed
Motor Development: *	<input type="radio"/> Definite Motor delay/impairment (verified by physical exam or unambiguous behavioral observation) <input type="radio"/> Probable Motor delay/impairment (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence) <input type="radio"/> Questionable Motor delay/impairment (not judged to be more likely than not, but with some indications of motor delay/impairment) <input type="radio"/> No Motor delay/impairment (no obvious indicators of 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 < 5 years old <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"/> Not Applicable < 5 years old/ High School graduate <input type="radio"/> Status Unknown
Primary Insurance at Follow-up: *	<input style="width: 100%;" type="text"/>
Specify:	<input style="width: 100%;" type="text"/>

Clinical Information					
Date of Measurement: *	<input style="width: 100%;" type="text"/>				
Height: *	<input style="width: 20%;" type="text"/> ft. <input style="width: 20%;" type="text"/> in.	<input style="width: 20%;" type="text"/> cm	<input type="radio"/> %ile	ST=	<input style="width: 100%;" type="text"/>
Weight: *	<input style="width: 20%;" type="text"/> lbs.	<input style="width: 20%;" type="text"/> kg	<input type="radio"/> %ile	ST=	<input style="width: 100%;" type="text"/>
BMI:	kg/m ²		<input type="radio"/> %ile		
Is growth hormone therapy used during this follow-up period: *	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK				
Urine Protein Found By Any Method:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK				
Diabetes onset during the follow-up period: *	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK				
If yes, insulin dependent:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK				
Bone Disease: *					
Fracture in the past year (or since last follow-up):	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK				
Specify Location and number of fractures:	<input type="checkbox"/> Spine-compression fracture	# of fractures:	<input style="width: 50%;" type="text"/>		
	<input type="checkbox"/> Extremity	# of fractures:	<input style="width: 50%;" type="text"/>		
	<input type="checkbox"/> Other	# of fractures:	<input style="width: 50%;" type="text"/>		
AVN (avascular necrosis):	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK				
Graft Status: *	<input type="radio"/> Functioning <input type="radio"/> 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=

Date of Failure:

Primary Cause of Graft Failure:

Other, Specify:

Contributory causes of graft failure:

Acute Rejection

YES NO UNK

Chronic Rejection

YES NO UNK

Graft Thrombosis

YES NO UNK

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

Other, Specify:

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:

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
- 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

Post Transplant Malignancies: *

YES NO UNK

Donor Related:

YES NO UNK

Recurrence of Pre-Tx Tumor:

YES NO UNK

Post Tx 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)

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

If Yes, check all that apply:

Specify:

Specify:

Treatment for BK (polyoma) virus:

YES NO

Yes, Immunosuppression reduction

Yes, Cidofovir

Yes, IVIG

Yes, Type Unknown

Yes, Other, Specify

If Yes, check all that apply:

Specify:

Other therapies:

YES NO

Photopheresis

Plasmapheresis

Total Lymphoid Irradiation (TLI)

If Yes, check all that apply:

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"/>