STARZL NETWORK

for Excellence in Pediatric Transplantation

NETWORK HELP REFERENCE GUIDE

Table of Contents

DATAMART USER GUIDE 3
HOW TO OBTAIN A STARZL NETWORK USER ACCOUNT 4
FORGOTTEN USERNAME OR PASSWORD 4
SESSION TIMEOUT 4
SUBJECT ELIGIBILITY 4
CONSENTING 4
LOGGING INTO THE REGISTRY 5
REGISTRIES SEARCH 5
Searching for patient records within Starzl Network Database 5
Identifying a patient's TRR ID 5
SUBJECT INFORMATION 6
DATA COLLECTION 6
DATA COLLECTION FORMS 7
Perioperative Details 7
Form at Discharge from Transplant Admission 7
Clinic Workflow Form: 30 Day Follow-Up Post Discharge 7
Clinic Workflow Form: Six Month Follow-Up Post Tx 7
Clinic Workflow Form: One Year, Two Year, Three Year, etc. Follow Up Post TX 7
Transfer of Care: Patient's First Adult Clinic Appointment 7
Transfer of Care: Three Month Follow-Up Post TX 7
Transfer of Care: Six Month Follow-Up Post TX 7
Transfer of care: One Year Follow-Up Post TX 7
Transfer of Care: Two Year Follow-Up Post TX 7
Transfer of Care: Three Year Follow-Up Post TX 7
DATA VISUALIZATIONS 8
DATA DICTIONARY 9
Perioperative Details 10
Form at Discharge from Transplant Admission 12
Clinic Workflow Form 15
Transition of Care 22
FREQUENTLY ASKED QUESTIONS 28
Subject Information 29
Perioperative Details Form 29
Form at Discharge from Transplant Admission 29
Clinic Workflow Form 30 Day Follow-up Post Discharge 30
Clinic Workflow Forms 30

DATAMART USER GUIDE

HOW TO OBTAIN A STARZL NETWORK USER ACCOUNT

- All centers with completed participation agreements will be granted access to add prospective Starzl data to their center's existing imported data and access to the Network Dashboards.
- Centers can determine the users they wish to have access. This could include hepatology, surgery, allied health, research coordinators and data coordinators at your centers.
- Centers should indicate the requested user access by sending name, role, and email to CJ Confair.
- To maintain data integrity, it is imperative that each person entering data enters the data from their own account. Do not share your user ID or password with anyone for any reason. Once you are finished with your data entry, be sure to log out of the network.

FORGOTTEN USERNAME OR PASSWORD

- If you have forgotten your username or password, please contact the helpdesk at starzl.support@unos.org

SESSION TIMEOUT

- The session will automatically timeout after inactivity. At this time your session will be terminated, and any unsaved work will be lost.

SUBJECT ELIGIBILITY

- The Starzl data portal will be pre-populated with OPTN center data between 2002 to present from participating U.S hospitals.
    - For stand-alone pediatric hospitals, transplants performed at the hospital are included, regardless of recipient age. Transplants at those programs where the recipient was 18,19 etc. years of age at transplant are included.
    - For combined adult and pediatric transplant facilities, only transplants for recipients less than 18 years of age at the time of transplant are included.
    - Subject eligibility will take place in two ways:
        - The first will be prospective transplants that occur after registry go live date. The form at transplant will be able to be completed within 24 hours of transplant. A transplant will also initiate the subsequent forms collected by the registry. (Forms will be generated automatically).
        - The second way to activate data entry is to complete appropriate forms on eligible patients by completing annual clinic follow-up forms and transition of care forms (these include data elements related to immunosuppression, quality of life and transition of care). The annual clinic forms will be available 2 months prior to the actual transplant anniversary.

CONSENTING

- When required by center policy, consent should be obtained by the center and documented according to center practice for prospective entry of data into the Starzl Database.
- The coordinating protocol is at UPMC Children's Hospital of Pittsburgh (CHP), and questions can be answered by Daniel Pieratt (pierattdw@upmc.edu).
- Deidentified audit of consents and consent logs will be reviewed by Daniel Pieratt on a quarterly basis.
- The retrospective uploading of patients at your center does not require consent since the OPTN data is included in the participation agreement.

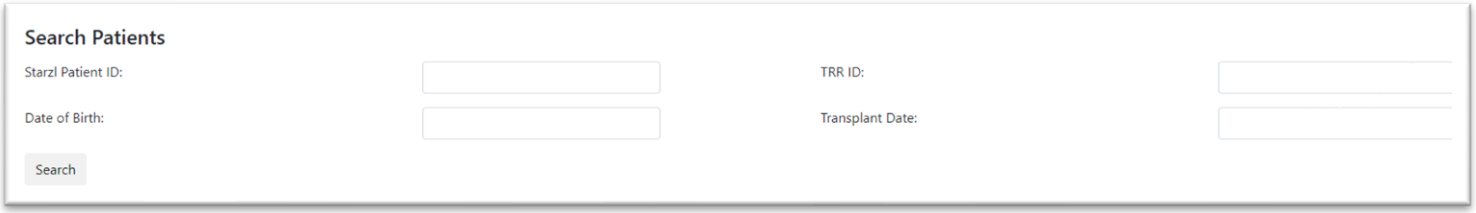
LOGGING INTO THE REGISTRY

- Via Starzl Network Site or
- Open your internet browser and navigate to https://starzl.unosregistries.org.
    - We suggest saving this page as a favorite for future navigation.
    - Enter your username and password and click submit
    - You will be taken to the Starzl Network Homepage

REGISTRIES SEARCH

Searching for patient records within Starzl Network Database

- Patients can be found in the Starzl Registry by utilizing one or multiple of the following search criteria:
    - Starzl Patient ID: Unique ID number assigned to each patient at the time of enrollment.
    - TRR ID: ID number associated with each recipient's UNOS Transplant Recipient Registration (TRR) form.
    - DOB: Recipient's date of birth
    - Transplant Date: Recipient's UNOS Transplant Date



Identifying a patient's TRR ID

Utilizing the UNOS data services portal, your center can create a custom report to identify each patient's unique TRR ID number.

- Log into UNOS
- Enter the data services portal
- Custom Report Builder

- New Report
- Select a Data Source: (Transplants performed at center) and at least the following criteria:
    - Recipient and Donor Identifies
        - Last Name
        - First Name
    - Transplant Procedure
        - Transplant Date
    - Recipient TRR
        - TRR ID
    - Organ Type
        - Liver
        - Liver/Kidney
    - Transplant Date
        - 01/01/2008- Current date
- Save and Run Report

If your center does not wish to create a running report of recipient's TRR ID numbers, you can look up individual TRR IDs through the UNOS TIEDI portal.

- Log into UNOS
- Select TIEDI
- Select "Patient History Search"
- Search for your individual patient
- Utilizing the hyperlinked name, select the correct patient and corresponding organ and transplant date
- A list of completed TEIDI forms will be listed with the corresponding Record IDs
- Locate the TRR form and the Record ID number
- Copy the TRR Record ID number and paste into the Starzl Network TRR ID search field

SUBJECT INFORMATION

This form will be completed at the time or registration. The information on this form will be utilized for patient identification.

- Transfer of care for each patient will be documented in this section.
    - Your center will indicate if transfer of care to an adult facility has started by selecting 'Yes' or 'No'
        - If 'Yes' is selected:
            - document the last pediatric clinic visit date.
            - the transfer of care for the patient will be initiated and subsequent transfer of care forms will be generated.

DATA COLLECTION

Data collection and submission can occur in two ways:

- Starzl Registry Forms
    - Data entered directly into the DataMart
    - Incomplete forms can be saved and completed later
    - User will be alerted of incomplete data elements
- Starzl Excel Templates
    - Data entered into excel spreadsheet
    - Includes all registry data fields and data definitions
    - File must be saved as a ".CSV" for upload

DATA COLLECTION FORMS

Data collection forms are generated automatically by the registry. To ensure accurate collection and recording of data, the Starzl Network has created a Data Completion Guideline which provides help documentation for each field throughout the registry. Please refer to the Data Dictionary when completing network forms.

Perioperative Details

- Can be completed within 24 hours of transplant.

Form at Discharge from Transplant Admission

- To be completed at hospital discharge or six weeks post-transplant, whichever is first.

Clinic Workflow Form: 30 Day Follow-Up Post Discharge

- Should include data between hospital discharge and 30 days post-transplant hospital discharge.
- Please utilize clinical visit data within +/- 7 days.
- PELTQL data available for completion, but not required on 30-day follow-up form.

Clinic Workflow Form: Six Month Follow-Up Post Tx

- To be completed six months post-transplant. Should include data between 30 day follow up visit and six month follow up post-transplant.
- Please utilize clinical visit data within +/- 2 months.

Clinic Workflow Form: One Year, Two Year, Three Year, etc. Follow Up Post TX

- Generated annually. Should only include information obtained since last follow-up period.
- Please utilize clinical visit data withing + / - 3 months.
- Social Determinants of Health
    - Intended to be completed by one member of the family

Transfer of Care: Patient's First Adult Clinic Appointment

- To be completed after the patient's first adult transplant clinic appointment.

Transfer of Care: Three Month Follow-Up Post TX

- To be completed three months after transition to adult care. Should only include information obtained since last follow-up period.

Transfer of Care: Six Month Follow-Up Post TX

- To be completed six months after transition to adult care. Should only include information obtained since last follow-up period.

Transfer of care: One Year Follow-Up Post TX

- To be completed one year after transition to adult care. Should only include information obtained since last follow-up period.

Transfer of Care: Two Year Follow-Up Post TX

- To be completed two years after transition to adult care. Should only include information obtained since last follow-up period.

Transfer of Care: Three Year Follow-Up Post TX

- To be completed three years after transition to adult care. Should only include information obtained since last follow-up period.

DATA VISUALIZATIONS

The registry offers interactive data visualizations which allow you to compare your center's outcomes to those in the network, non-network, and national centers. Data visualizations include:

- Overview
  - Post-transplant and post-listing outcomes (5-year Kaplan Meier Patient Survival)
  - Outcome after transplant candidate listing
  - Form completion over time
- Perioperative practices including anticoagulation
  - Percentage of recipients with post-transplant vascular complications
  - Recipient length of stay
- Optimizing Immunosuppression
  - Post-transplant outcomes
  - Percentage of registry patients with ALT < 50
  - Recipient post-transplant immunosuppression regimen
- Quality of Life
  - Percentage of PeLTQL- eligible recipients who completed a survey
  - PeLTQL scores for parents and children
- Understanding Variations in Transition of Care Resources and Practices
  - Number of recipients transferring to adult care
  - Complications reported after transfer of care

STARZL NETWORK

for Excellence in Pediatric Transplantation

DATA DICTIONARY

Perioperative Details		
Field Name	**Section**	**Help Documentation**
Operative Details:	**Recipient**	
Operative Time (min)	**Recipient**	Enter the operative time (minutes). Calculate the operative time utilizing the surgery/incision start and end times. (not anesthesia start and end).
Warm Ischemic Time (min)	**Recipient**	Enter the warm ischemic time (minutes). This accounts for the interval between the beginning of anastomosis and reperfusion.
Pre-existing donor hypercoagulable disorder?	**Donor**	Indicate if the donor had pre-existing hypercoagulable disorder ('Yes' or 'No'). **If 'Yes' is selected, then address the following**: • **If yes, specify type of disorder**: Specify pre-existing donor hypercoagulable disorder in the text box.
Graft weight	**Donor**	Enter the donor graft weight (grams).
Donor Injury?	**Donor**	Select the donor injury utilizing the multi-select checkboxes shown: 'None', 'Arterial injury/intimal tear', 'Donor steatosis', 'Donor documented down time> 30 minutes', or 'Donor traumatic laceration'.
Estimated Blood Loss (ml)	**Intra-Op**	Enter the estimated blood loss (mL).
Estimated Blood Loss (mL/kg)	**Intra-Op**	System calculated variable that divides the 'Estimated Blood Loss (mL)' from the 'Recipient Weight (kg)' to equate the 'Estimated Blood Loss (mL/kg)'.
Center Anticoagulation Protocol Started Intraop?	**Intra-Op**	Indicate if center's blood loss protocol was started intraoperatively ('Yes' or 'No'). **If 'No' is selected, then address the following**: • **If No, why**: Specify why the center's blood loss protocol was not started in the text box.
Held after start?	**Intra-Op**	Indicate if center protocol was stopped intraoperatively ('Yes' or 'No').
Intraop ultrasound?	**Intra-Op**	Indicate if intraoperative ultrasound was performed ('Yes' or 'No'). **If 'Yes' is selected, then address the following:** • **Artery ultrasound adequate**: Indicate if intraoperative ultrasound was performed and artery waveform was adequate ('Yes' or 'No'). • **PV ultrasound adequate:** Indicate if intraoperative ultrasound was performed and PV waveform was adequate ('Yes' or 'No').
Biliary anastomosis	**Intra-Op**	Select the biliary anastomosis type from the options listed: 'Roux', 'Duct to Duct', or 'Other, Specify'. **If 'Other, specify' is selected, then address the following:** • **Other, specify:** Specify pre-existing donor hypercoagulable disorder in the text box.
Number of Biliary anastomosis	**Intra-Op**	Enter the number of biliary anastomosis (numeric value).
Arterial flow (if measured)	**Intra-Op**	Numeric value. If intraoperative flow measurements were done, document in mL/min.

Perioperative Details		
Field Name	**Section**	**Help Documentation**
PV flow (if measured)	**Intra-Op**	Numeric value. If intraoperative flow measurements were done, document in mL/min.
Intraop Thromboelastography	**Intra-Op**	Indicate if Intraop Thromoelastography was utilized ('Yes' or 'No').
On-table thrombosis?	**Intra-Op**	Select thrombosis type utilizing the multi-select checkboxes shown: 'None', 'HA', 'PV', 'HV', 'Artery Graft', 'Vein Graft', or 'Other, Specify'. **If 'HA', 'PV', 'HV', 'Artery Graft', 'Vein Graft', or 'Other, specify' is selected, then address the following**: • **Resolved:** Indicate if thrombosis has been resolved ('Yes' or 'No'). **If 'Other, specify' is selected, then address the following:** • **Other, specify**: Specify thrombosis type in the text box.
Abdomen closure POD (0=close at end of case. Otherwise, day besides 0 is day that the abdomen was closed either with skin or full fascia)	**Intra-Op**	Indicate post-op day for abdominal closure (days). **Note: if abdomen was closed at time of transplant POD = 0.**
Protocol started Post-Operation Day 0 (POD)	**Intra-Op**	Indicate if center's abdominal closure protocol was implemented on post-op day 0 (Date of Transplant) ('Yes' or 'No'). **If 'No' is selected, then address the following**: • **If No, Comment:** Indicate why the center's abdominal closure protocol was not implemented on POD 0.
Prostin (within perioperative period)	**Intra-Op**	Indicate if Prostin was utilized ('Yes' or 'No').

Form at Discharge from Transplant Admission		
Field Name	**Section**	**Help Documentation**
Diabetes observed prior to transplant event?	**Recipient**	Indicate if the patient had diabetes prior to transplant ('Yes', 'No', 'Unknown').
Date of discharge from ICU following Transplant	**Recipient**	Enter the date the patient was discharged from the ICU following the transplant procedure (mm/dd/yyyy).
Initial Transplant ICU Length of Stay (LOS)	**Recipient**	Calculated variable that subtracts the ' ICU Discharge Date' from the 'Transplant Date' to equate the 'Initial Transplant ICU Length of Stay (LOS)'.
Anticoagulation at Discharge	**Recipient**	Select the anticoagulation type at hospital discharge from the options listed: 'None', 'ASA', 'Lovenox', 'Other, Specify'. **If 'Yes' is selected, then address the following:** • **Other, specify**: Specify the anticoagulation medication in the text box.
Vascular Post-Op Event	**Post-Op**	This field will capture the number of Vascular Post-Op Events with the following options: 'No', 'Yes, 1', 'Yes, 2', 'Yes, 3', 'Yes, 4', or 'Yes, 5'. **Note: The 'Type of Event:', 'Comment on Event:', 'POD', and 'Protocol active during event?' will be collected for each post-Op event instance** **If 'Yes, 1', 'Yes, 2', 'Yes, 3', 'Yes, 4', or 'Yes, 5' is selected, then address the following:** • **Type of Event:** Select the post-op event corresponding to the options listed: 'Hepatic artery thrombosis (HAT)', Portal vein thrombosis (PVT)', 'Hepatic vein thrombosis (HVT)', 'Return to the OR for Bleeding', 'Held anticoag', 'PRBC (packed red blood cells)', 'FFP (fresh frozen plasma)', or 'CRYO'. • **Comment on Event:** Provide comments on the post-Op event in the text box. • **POD:** Indicate the Post-Operative Day (POD) that the Post-Op Event occurred on (numeric value). • **Anticoagulation Protocol active during event?** Indicate if the center's protocol was active at time of Post-Op Event ('Yes' or 'No').
Social Determinants of Health Questions	**Social Determinants Of Health**	**Help Documentation**
How hard is it for you to pay for the very basics like food, housing, medical care, and heat?	**Social Determinants Of Health**	Select how hard it is for the recipient to pay for the very basics like food, housing, medical care, and heat from the options listed: 'Not hard at all', 'Somewhat hard', or 'Very hard'.

Form at Discharge from Transplant Admission		
Field Name	**Section**	**Help Documentation**
What is your housing situation today?	**Social Determinants Of Health**	Select what the recipient's housing situation is today from the options listed: 'I have a steady place to live', 'I have a place to live today, but I am worried about losing it in the future', or 'I do not have a steady place to live (I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park)'.
Think about the place you live. Do you have problems with any of the following? (Check all that apply)	**Social Determinants Of Health**	Select all choices that apply by utilizing the multi-select checkboxes shown: 'Pests such as bugs, ants, or mice', 'Mold', 'Lead paint or pipes', 'Lack of heat', 'Oven or stove not working', 'Smoke detectors missing or not working', 'Water leaks', or 'None of the above'.
Within the past 12 months, you worried that your food would run out before you got money to buy more.	**Social Determinants Of Health**	Select if within the past 12 months, the recipient worried their food would run out before they got money to buy more from the options listed: 'Often true', 'Sometimes true', or 'Never true'.
Within the past 12 months, the food you bought just didn't last and you didn't have money to get more.	**Social Determinants Of Health**	Select if within the past 12 months, the recipient bought food that didn't last and didn't have money to get more from the options listed: 'Often true', 'Sometimes true', or 'Never true'.
In the past 12 months, has lack of reliable transportation kept you from medical appointments, meetings, work or from getting things needed for daily living?	**Social Determinants Of Health**	Indicate if within the past 12 months, the recipient has been kept from medical appointments, meetings, work, or from getting things needed for daily living due to the lack of reliable transportation ('Yes' or 'No').
In the past 12 months has the electric, gas, oil, or water company threatened to shut off services in your home?	**Social Determinants Of Health**	Select if within the past 12 months, the recipient has had the electric, gas, oil, or water company threaten to shut off services in the home from the options listed: 'Yes', 'No', or 'Already shut off'.
How often does anyone, including family and friends, physically hurt you?	**Social Determinants Of Health**	Select how often anyone, including family and friends, physically hurt you from the options listed: 'Never', 'Rarely', 'Sometimes', 'Fairly often', or 'Frequently'.

Form at Discharge from Transplant Admission		
Field Name	**Section**	**Help Documentation**
How often does anyone, including family and friends, insult or talk down to you?	**Social Determinants Of Health**	Select how often anyone, including family and friends, insult or talk down to you from the options listed: 'Never', 'Rarely', 'Sometimes', 'Fairly often', or 'Frequently'.
How often does anyone, including family and friends, threaten you with harm?	**Social Determinants Of Health**	Select how often anyone, including family and friends, threaten you with harm from the options listed: 'Never', 'Rarely', 'Sometimes', 'Fairly often', or 'Frequently'.
How often does anyone, including family and friends, scream or curse at you?	**Social Determinants Of Health**	Select how often anyone, including family and friends, scream or curse at you from the options listed: 'Never', 'Rarely', 'Sometimes', 'Fairly often', or 'Frequently'.

Clinic Workflow Form		
Field Name	**Section**	**Help Documentation**
Date of Visit	**General**	Enter the date of clinic visit (mm/dd/yyyy).
Tacrolimus	**Lab Values**	Indicate if patient is taking Tacrolimus ('Yes' or 'No'). **If 'Yes' is selected, then address the following:** • **Desired Tacrolimus goal trough levels**: Select the patients desired tacrolimus goal trough levels from the options listed: '< 3', '3-5', '5-8', '8-10' or '> 10'. • **Tacrolimus level at/prior to visit**: Enter the patient's outpatient tacrolimus level at or prior to clinic visit (numeric value). • **Second to last Tacrolimus level at/prior to visit**: Enter the patient's second to last outpatient tacrolimus level at or prior to clinic visit (numeric value). • **Third to last Tacrolimus level at/prior to visit**: Enter the patient's third to last outpatient tacrolimus level at or prior to clinic visit (numeric value).
The Medication Level Variability Index (MLVI): Standard Deviation of Tacrolimus level	**Lab Values**	System calculated variable that takes the Standard Deviation of the 'Tacrolimus level at/prior to visit', 'Second to last Tacrolimus level at/prior to visit', and 'Third to last Tacrolimus level at/prior to visit' values.
Additional Immunosuppression:	**Lab Values**	Select patient's immunosuppression mediations at the time of clinic visit.
mTOR inhibitors (Any)	**Lab Values**	Indicate if patient is prescribed any mTOR inhibitors ('Yes' or 'No').
MMF (any Mycophenolic acid)	**Lab Values**	Indicate if patient is prescribed MMF at time of clinic visit ('Yes' or 'No').
Steroids (prednisone, methylprednisolone, Solumedrol, Medrol)	**Lab Values**	Indicate if patient is prescribed steroids ('Yes' or 'No').
Other	**Lab Values**	Indicate if patient is prescribed other immunosuppressive medications ('Yes' or 'No'). **If 'Yes' is selected, then address the following**: • **Other, specify**: Enter the other immunosuppressive medications in the text box.
Anti-Hypertension medications	**Lab Values**	Indicate if patient is prescribed Anti-Hypertension medications at the time of clinic visit ('Yes' or 'No').
Anti-seizure medications	**Lab Values**	Indicate if patient is prescribed Anti-seizure medications at the time of clinic visit ('Yes' or 'No').

Clinic Workflow Form		
Field Name	**Section**	**Help Documentation**
Laboratory Markers:	**Lab Values**	
Date lab values were drawn:	**Lab Values**	Enter the date of patient's clinic labs were drawn (mm/dd/yyyy).
GGT	**Lab Values**	Enter patient's outpatient GGT level (U/L).
AST	**Lab Values**	Enter patient's outpatient AST level (U/L).
ALT	**Lab Values**	Enter patient's outpatient ALT level (U/L).
Albumin	**Lab Values**	Enter patient's outpatient albumin level (g/dL).
Platelet count	**Lab Values**	Enter the patient's outpatient platelet count (x10^9/L)
Was CMV/EBV PCR taken?	**Lab Values**	Indicate if CMV/EBV PCR was drawn ('Yes' or 'No'). **If 'Yes' is selected, then address the following**: • **Date of CMV/EBV PCR taken:** Enter the date of the patient's CMV/EBV labs (mm/dd/yyyy). Include the most recent value since the last clinic workflow form. • **CMV PCR?** Select the patient's CMV PCR results from the options listed: 'Negative', 'Positive', or 'Unknown'. **If 'Positive' is selected, then address the following:** • **On anti-viral therapy?** Indicate if the patient is on anti-viral therapy ('Yes', 'No', or 'Unknown'). • **EBV PCR?** Select the patient's EBV PCR results from the options listed: 'Negative', 'Positive' or 'Unknown'. **If 'Positive' is selected, then address the following:** • **On anti-viral therapy?** Indicate if the patient is on anti-viral therapy ('Yes', 'No', or 'Unknown').
Lipid Panel:	**Lab Values**	
Cholesterol	**Lab Values**	Enter the patient's outpatient Cholesterol level (mg/dL).
HDL	**Lab Values**	Enter the patient's outpatient HDL level (mg/dL).
Triglyceride	**Lab Values**	Enter the patient's outpatient Triglyceride level (mg/dL).
Interim Interventions and Complications		

Clinic Workflow Form		
Field Name	**Section**	**Help Documentation**
Was DSA measured since last follow-up visit	**Graft-related Events**	Indicate if the patient's DSA's were measured since their last follow-up visit ('Yes' or 'No'). **If 'Yes' is selected, then address the following**: • **Date DSA was measured**: Enter the date the patient's last DSA was obtained (mm/dd/yyyy). • **Class 1 DSA**: Indicate the patient's result ('Detected' or 'Not Detected'). • **Class 2 DSA**: Indicate the patient's result ('Detected' or 'Not Detected'). • **If yes, (paste here) report**: Copy and paste report in text box.
Liver biopsy since last follow-up visit?	**Graft-related Events**	This field will capture the number of biopsies since last follow-up visit with the following options: 'No', 'Yes, 1', 'Yes, 2', 'Yes, 3', 'Yes, 4', or 'Yes, 5'. **Note: The 'Date of Biopsy:', 'For cause? For surveillance?', 'Acute Rejection (biopsy proven or clinical)', 'Chronic Rejection (biopsy proven or clinical)', and 'Rejection biopsy summary report (paste here)' will be collected for each biopsy since last follow-up visit** **If 'Yes, 1', 'Yes, 2', 'Yes, 3', 'Yes, 4', or 'Yes, 5' is selected, then address the following**: • **Date of Biopsy**: Enter the date of patient's biopsy(s) (mm/dd/yyyy). • **Indication liver biopsy**: Indicate if the biopsy was ('For cause' or 'For surveillance'). • **Acute Rejection (biopsy proven)**: Indicate if the patient had a biopsy or clinical proven acute rejection ('Yes', 'No', or 'Unknown'). • **Chronic Rejection (biopsy proven)**: Indicate if the patient had a biopsy or clinical proven chronic rejection ('Yes', 'No', or 'Unknown'). • **Liver biopsy pathology report (please paste text here, EXCLUDING patient identifiers)**: Copy and paste report in text box.
History of biliary interventions since last follow-up visit?	**Graft-related Events**	Indicate if the patient had any biliary interventions since their last follow-up visit ('Yes' or 'No'). **If 'Yes' is selected, then address the following:** • **Date of Intervention**: Enter date of intervention (mm/dd/yyyy). • **Intervention performed**: Select the intervention type from the options listed: 'PTC', 'ERCP', 'Surgical revision' or 'Other, Specify'. **If 'Other, specify' is selected, address the following:** • **Other, specify:** Specify the intervention type in the text box.

Clinic Workflow Form		
Field Name	**Section**	**Help Documentation**
Vascular Thrombosis observed since last follow-up visit?	**Graft-related Events**	Indicate if patient had vascular thrombosis since last follow-up visit ('Yes' or 'No'). **If 'Yes' is selected, then address the following:** • **<u>If yes, select</u>:** Select the type of thrombosis from the options listed: 'Hepatic artery', 'Hepatic vein' or 'Portal vein'. • **<u>If yes, date:</u>** Enter date of intervention (mm/dd/yyyy).
Vascular Interventions observed since last follow-up visit?	**Graft-related Events**	Indicate if patient had vascular interventions since last follow-up visit ('No', 'Yes, 1', 'Yes, 2', 'Yes, 3'). **Note: The 'If Yes, then type:', 'Date of Intervention:', 'Procedure:', and 'Other, specify' will be need to be collected for each vascular intervention observed since last follow-up visit** **If 'Yes, 1', 'Yes, 2', 'Yes, 3' is selected, then address the following:** • **<u>If yes, then type</u>**: Select the type of vascular intervention from the options listed: 'Hepatic artery', 'Hepatic vein' or 'Portal vein'. • **<u>Date of Intervention</u>:** Indicate the date of vascular intervention (mm/dd/yyyy). • **<u>Procedure</u>:** Select the procedure type from the options listed: ' Thrombectomy', 'Dilation', 'Surgical Revision' or 'Other, Specify'. **If 'Other, specify' is selected, address the following**: • **<u>Other, specify</u>**: Specify the type of procedure in the text box.
Infection since last follow-up requiring IV anti-infective medications?	**Graft-related Events**	Indicate the infection type requiring IV utilizing the multi-select checkboxes shown: 'None', 'Bacterial', 'Fungal', 'Viral' or 'Other, Specify'. **If 'Other, specify' is selected, address the following**: • **<u>Other, specify</u>**: Specify the type of infection in the text box.
Anticoagulation since last follow-up visit?	**Graft-related Events**	Indicate the anticoagulation type from the options listed: 'None', 'ASA', 'Lovenox', 'Other, Specify'. **If 'Other, specify' is selected, address the following**: • **<u>Other, specify</u>**: Specify the type of anticoagulation in the text box.
Pertinent imaging since last clinic visit?	**General**	Indicate if patient had pertinent imaging since last follow-up visit ('Yes' or 'No'). **If 'Yes' is selected, then address the following:** • **<u>Select the imaging</u>**: Select imaging type utilizing the multi-select checkboxes shown: 'US', 'MRCP', 'CT', or 'PTC'. • **<u>Imaging report (please paste text here, EXCLUDING patient identifiers)</u>**: Copy and past image text in text box.

Clinic Workflow Form		
Field Name	**Section**	**Help Documentation**
Has the patient been hospitalized since the last patient status visit:	**General**	Indicate if patient has been hospitalized since the last follow-up visit ('No', 'Yes, 1', 'Yes, 2', 'Yes, 3'). **Note: The 'Date of admission:' and 'Date of discharge:' will be need to be collected for each patient hospitalization since last follow-up visit** **If 'Yes, 1', 'Yes, 2', 'Yes, 3' is selected, then address the following**: • **Date of admission**: Enter the date of hospital admission (mm/dd/yyyy). • **Date of discharge**: Enter the date of hospital discharge (mm/dd/yyyy).
PeLTQL Scores:	**PeLTQL**	
Date at completing PeLTQL	**PeLTQL**	Enter the date the PeLTQL form is being completed (mm/dd/yyyy).
Age at completing PeLTQL	**PeLTQL**	Enter the age that the PeLTQL form is being completed at (years).
Language version for completing PeLTQL	**PeLTQL**	Select the language version for completing the PeLTQL: 'English', 'Spanish', 'French', 'Other, Specify'. **If 'Other, specify' is selected, then address the following:** • **Other, specify**: Indicate the language in the text box.
What was the completion format?	**PeLTQL**	Select the completion format from the options listed: 'Pen/Paper', 'iPad', 'Phone App'.
Who completed the parent version?	**PeLTQL**	Specify which parent completed the form from the options listed: 'Mom', 'Dad', 'Other, Specify'. **If 'Other, specify' is selected, then address the following:** • **Other, specify: Indicate who completed the form in the text box.**
FK level on the day the PeLTQL is completed	**PeLTQL**	Enter the patient's FK level from the date the PeLTQL form was completed (numeric value).
Patient_Total PeLTQL Score	**PeLTQL**	Enter the patient's total PeLTQL score (numeric value).
Parent - Total PeLTQL Score	**PeLTQL**	Enter the parent's total PeLTQL score (numeric value).
Patient - Future Health (sub-domain score)	**PeLTQL**	Enter the Patient's future health sub-domain score (numeric value).
Parent - Future Health (sub-domain score)	**PeLTQL**	Enter the Parent's future health sub-domain score (numeric value).
Patient - Coping and Adjustment (sub-domain score)	**PeLTQL**	Enter the patient's coping and adjustment score (numeric value).

Clinic Workflow Form		
Field Name	**Section**	**Help Documentation**
Parent - Coping and Adjustment (sub-domain score)	**PeLTQL**	Enter the parent's coping and adjustment score (numeric value).
Patient - Social Emotional (sub-domain score)	**PeLTQL**	Enter the patient's social emotional score (numeric value).
Parent - Social Emotional (sub-domain score)	**PeLTQL**	Enter the parent's social emotional score (numeric value).
Social Determinants of Health section collected at (1 yr. post-TX, 2 yr. post-TX, 3 yr. post-TX, and 4 yr. post-TX)		
Social Determinants of Health Questions	**Social Determinants Of Health**	*** Intended to be completed by one caregiver of the family
How hard is it for you to pay for the very basics like food, housing, medical care, and heat?	**Social Determinants of Health**	Select how hard it is for the recipient to pay for the very basics like food, housing, medical care, and heat from the options listed: 'Not hard at all', 'Somewhat hard', or 'Very hard'.
What is your housing situation today?	**Social Determinants of Health**	Select what the recipient's housing situation is today from the options listed: 'I have a steady place to live', 'I have a place to live today, but I am worried about losing it in the future', or 'I do not have a steady place to live (I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park)'.
Think about the place you live. Do you have problems with any of the following? (Check all that apply)	**Social Determinants of Health**	Select all choices that apply by utilizing the multi-select checkboxes shown: 'Pests such as bugs, ants, or mice', 'Mold', 'Lead paint or pipes', 'Lack of heat', 'Oven or stove not working', 'Smoke detectors missing or not working', 'Water leaks', or 'None of the above'.
Within the past 12 months, you worried that your food would run out before you got money to buy more?	**Social Determinants of Health**	Select if within the past 12 months, the recipient worried their food would run out before they got money to buy more from the options listed: 'Often true', 'Sometimes true', or 'Never true'.
Within the past 12 months, the food you bought just didn't last and you didn't have money to get more.	**Social Determinants of Health**	Select if within the past 12 months, the recipient bought food that didn't last and didn't have money to get more from the options listed: 'Often true', 'Sometimes true', or 'Never true'.

Clinic Workflow Form		
Field Name	**Section**	**Help Documentation**
In the past 12 months, has lack of reliable transportation kept you from medical appointments, meetings, work or from getting things needed for daily living?	**Social Determinants of Health**	Indicate if within the past 12 months, the recipient has been kept from medical appointments, meetings, work, or from getting things needed for daily living due to the lack of reliable transportation ('Yes' or 'No').
In the past 12 months has the electric, gas, oil, or water company threatened to shut off services in your home?	**Social Determinants of Health**	Select if within the past 12 months, the recipient has had the electric, gas, oil, or water company threaten to shut off services in the home from the options listed: 'Yes', 'No', or 'Already shut off'.
How often does anyone, including family and friends, physically hurt you?	**Social Determinants Of Health**	Select how often anyone, including family and friends, physically hurt you from the options listed: 'Never', 'Rarely', 'Sometimes', 'Fairly often', or 'Frequently'.
How often does anyone, including family and friends, insult or talk down to you?	**Social Determinants Of Health**	Select how often anyone, including family and friends, insult or talk down to you from the options listed: 'Never', 'Rarely', 'Sometimes', 'Fairly often', or 'Frequently'.
How often does anyone, including family and friends, threaten you with harm?	**Social Determinants Of Health**	Select how often anyone, including family and friends, threaten you with harm from the options listed: 'Never', 'Rarely', 'Sometimes', 'Fairly often', or 'Frequently'.
How often does anyone, including family and friends, scream or curse at you?	**Social Determinants Of Health**	Select how often anyone, including family and friends, scream or curse at you from the options listed: 'Never', 'Rarely', 'Sometimes', 'Fairly often', or 'Frequently'.

Transition of Care		
Field Name	**Section**	**Help Documentation**
Transition of Care		
Was a transition program available?	**Pre-Transition**	Indicate if a transition program was available ('Yes' or 'No' 'Unknown').
Did the patient participate in the transition program?	**Pre-Transition**	Select if the patient participated in the transition program from the options listed: ' Yes', 'No', 'Unknown', or 'Program not available'.
Last peds clinic appointment	**Pre-Transition**	Enter the date of patient's last pediatric clinic appointment (mm/dd/yyyy).
Last contact: Pediatrics (LCP)	**Pre-Transition**	Enter the date of patient's last contact with pediatric facility as defined by type of LPFC (mm/dd/yyyy).
Type of LCP	**Pre-Transition**	Select the last type of contact with pediatric facility from the options listed: 'Clinic', 'ER', 'Admission to hospital', 'Phone call/email/text', 'Other, Specify'. **If 'Other, specify' is selected, then address the following:** • **Other, specify:** Specify the last type of contact with pediatric facility in the text box.
First adult clinic appointment		Enter the date of the patient's first adult clinic appointment (mm/dd/yyyy).
First contact: Adult facility (FCA)		Enter the date of the patient's first contact with the adult facility (mm/dd/yyyy).
Type of FCA		Select the first type of contact with adult facility from the options listed: 'Clinic', 'ER', 'Admission to hospital', 'Phone call/email/text', 'Other, Specify'. **If 'Other, specify' is selected, then address the following:** • **Other, specify:** Specify the last type of contact with pediatric facility in the text box.
Education level at transfer	**Pre-Transition**	Select the patient's education level at time of transfer from the options listed: 'Some HS', 'Graduated HS', 'Technical/Trade School', 'Some college', 'Graduated college', 'Unknown', or 'Other, Specify'. **If 'Other, specify' is selected, then address the following:** • **Other, specify:** Specify the patient's education level at time of transfer in the text box.
Employment at transfer	**Pre-Transition**	Select the patient's employment status at the time of transfer from the options listed: 'Part time', 'Full time', 'Unemployed', 'Not applicable', or 'Unknown'.
Insurance at transfer	**Pre-Transition**	Select the patient's insurance type at the time of transfer from the options listed: 'Private', 'Government', 'Uninsured', or 'Unknown'.
Cognitive delay	**Pre-Transition**	Indicate if the patient has cognitive delays ('Yes', 'No', 'Unknown').
Substance abuse history	**Pre-Transition**	Indicate if the patient has substance abuse ('Yes', 'No', 'Unknown').

Transition of Care		
Field Name	**Section**	**Help Documentation**
Social support	**Pre-Transition**	Select the patient's level of social support from the options listed: 'Living with parents', 'Living independently', 'Under guardianship', 'Detention', Foster Home', 'Supervised Living',; Unknown', 'Other, Specify'. **If 'Other, specify' is selected, then address the following:** • **Other, specify:** Specify the patient's level of social support in the text box.
Adherence history (meds, labs, clinic)		Indicate if the patient has a history of nonadherence to medications, labs, clinic appointments ('Yes', No', Unknown'). **If 'Yes' is selected, then identify the type of non-adherence:** •' Medications', 'Lab follow-up', 'Clinic follow-up'.
Laboratory Values:	**Lab Values**	
Labs at/prior to LCP:		
Tacrolimus level	**Lab Values**	Indicate the patient's outpatient tacrolimus level at or prior to LCP visit (numeric value).
ALT level	**Lab Values**	Indicate the patient's outpatient ALT level at or prior to LCP visit (U/L).
Platelets level	**Lab Values**	Indicate the patient's outpatient platelet level at or prior to LCP visit (x10^9/L).
Second to last labs at/prior to LCP:		
Tacrolimus level	**Lab Values**	Indicate the patient's second to last outpatient tacrolimus level at or prior to LCP visit (numeric value).
ALT level	**Lab Values**	Indicate the patient's second to last outpatient ALT level at or prior to LCP visit (U/L).
GGTP level	**Lab Values**	Indicate the patient's second to last outpatient GGTP level at or prior to LCP visit (U/L).
Platelets level	**Lab Values**	Indicate the patient's second to last outpatient platelet level at or prior to LCP visit (x10^9/L).
Third to last labs at/prior to LCP:		
Tacrolimus level	**Lab Values**	Indicate the patient's third to last outpatient tacrolimus level at or prior to LCP visit (numeric value).
ALT level	**Lab Values**	Indicate the patient's third to last outpatient ALT level at or prior to LCP visit (U/L).
GGTP level	**Lab Values**	Indicate the patient's third to last outpatient GGTP level at or prior to LCP visit (U/L).
Platelets level	**Lab Values**	Indicate the patient's third to last outpatient platelet level at or prior to LCP visit (x10^9/L).

Transition of Care		
Field Name	**Section**	**Help Documentation**
The Medication Level Variability Index (MLVI): Standard Deviation of Tacrolimus level	**Lab Values**	System calculated variable that takes the Standard Deviation of the 'Tacrolimus level at/prior to LCP visit', 'Second to last Tacrolimus level at/prior to LCP visit', and 'Third to last Tacrolimus level at/prior to LCP visit' values.
Labs at FCA:		
Tacrolimus level	**Lab Values**	Indicate the patient's outpatient tacrolimus level at or prior to FCA visit (numeric value).
ALT level	**Lab Values**	Indicate the patient's outpatient ALT level at or prior to FCA visit (U/L).
GGTP level	**Lab Values**	Indicate the patient's outpatient GGTP level at or prior to FCA visit (U/L).
Platelet level	**Lab Values**	Indicate the patient's outpatient platelet level at or prior to FCA visit (x10^9/L).
Patient Status:	**Post-Transition**	
Hospital admission after last pediatric contact	**Post-Transition**	Indicate if the patient was admitted to the hospital after their last contact with pediatrics ('Yes' or 'No').
Reason for admission	**Post-Transition**	Select the reason for hospital admission from the options listed: 'Rejection', 'Infection', 'Biliary issues', 'Not transplant-related', 'Unknown', 'Not applicable', 'Other, Specify'. **If 'Other, specify' is selected, then address the following:** • **Other, specify:** Specify the reason for hospital admission in the text box.
Current Status post-transfer	**Post-Transition**	Select the patient's status post-transfer from the options listed: 'Alive', 'Dead', or 'Unknown'. **If 'Alive' is selected, then address the following**: • **Post transfer: acute rejection**: Indicate if the patient experienced acute rejection episodes at adult facility ('Yes', 'No') • **Post transfer: chronic rejection**: Indicate if the patient developed chronic rejection episodes at adult facility ('Yes', 'No') • **Post transfer**: **retransplant:** Indicate if the patient has been retransplanted ('Yes', 'No') • **If 'Yes' is selected, then address the following:** • I**ndication for retransplant**: Select the appropriate indication for retransplant: 'Chronic Rejection', 'Infection', 'Recurrent Disease', 'Substance Abuse', 'Unknown', ' Other, Specify'

Transition of Care		
Field Name	**Section**	**Help Documentation**
New onset comorbidities	**Post-Transition**	Select the new onset comorbidities from the options listed: 'None observed', 'Hypertension', 'Diabetes', 'Hyperlipidemia', 'Decreased bone density', 'Substance abuse', 'Increased BMI', or 'New mental health diagnosis' 'Other, specify'. **If 'Other, specify' is selected, then address the following:** • Other, specify: Specify the new onset comorbidity in the text box.
Reproductive health (male/female)	**Post-Transition**	Select the reproductive health utilizing the multi-select checkboxes shown: 'Not applicable', 'Live birth', 'Still birth', 'Fetal loss', 'Infertility', 'Newborn death within 30 days', 'Other, Specify'. **If 'Other, specify' is selected, address the following:** • **Other, specify:** Specify the reproductive health in the text box.

Transition of Care		
Field Name	**Section**	**Help Documentation**
Hospital admission after Transfer of Care	**Post-Transition**	Indicate if patient was admitted to the hospital post-transition: '< 3 months', '3-6 months', '7-12 months', '13-24 months', '25-36 months'
Reason for admission	**Post-Transition**	Select the reason for hospital admission from the options listed: 'Rejection', 'Infection', 'Biliary issues', 'Not transplant-related', 'Unknown', 'Not applicable', 'Other, Specify'. **If 'Other, specify' is selected, then address the following:** • **Other, specify:** Specify the reason for hospital admission in the text box.
Current Status post-transfer	**Post-Transition**	Select the patient's status post-transfer from the options listed: 'Alive', 'Dead', or 'Unknown'. **If 'Alive' is selected, then address the following**: • **Post transfer: acute rejection**: Indicate if the patient experienced acute rejection episodes at adult facility ('Yes', 'No') • **Post transfer: chronic rejection**: Indicate if the patient developed chronic rejection episodes at adult facility ('Yes', 'No') • **Post transfer**: **retransplant:** Indicate if the patient has been retransplanted ('Yes', 'No') • **If 'Yes' is selected, then address the following:** • I**ndication for retransplant**: Select the appropriate indication for retransplant: 'Chronic Rejection', 'Infection', 'Recurrent Disease', 'Substance Abuse', 'Unknown', ' Other, Specify'
Adherence history (meds, labs, clinic)	**Post-Transition**	Indicate if the patient has a history of nonadherence to medications, labs, clinic appointments ('Yes', No', Unknown'). **If 'Yes' is selected, then identify the type of non-adherence:** •' Medications', 'Lab follow-up', 'Clinic follow-up'.
New onset comorbidities	**Post-Transition**	Select the new onset comorbidities from the options listed: 'None observed', 'Hypertension', 'Diabetes', 'Hyperlipidemia', 'Decreased bone density', 'Substance abuse', 'Increased BMI', or 'New mental health diagnosis' 'Other, specify'. **If 'Other, Specify' is selected, then address the following:** • Other, Specify: Specify the new onset comorbidity in the text box.
Reproductive health (male/female)	**Post-Transition**	Select the reproductive health utilizing the multi-select checkboxes shown: 'Not applicable', 'Live birth', 'Still birth', 'Fetal loss', 'Infertility', 'Newborn death within 30 days', 'Other, Specify'. **If 'Other, Specify' is selected, address the following:** • **Other, Specify:** Specify the reproductive health in the text box.

Transition of Care		
Field Name	**Section**	**Help Documentation**
Post-transfer labs at 6 months:		
Tacrolimus level	**Lab Values**	Indicate the patient's outpatient tacrolimus level at 6 months post-transfer to adult facility (Numeric value).
ALT level	**Lab Values**	Indicate the patient's outpatient ALT level at 6 months post-transfer to adult facility (U/L).
GGTP level	**Lab Values**	Indicate the patient's outpatient GGTP level at 6 months post-transfer to adult facility. (U/L).
Platelet level	**Lab Values**	Indicate the patient's outpatient platelet level at 6 months post-transfer to adult facility. (x10^9/L).

FREQUENTLY ASKED QUESTIONS

Subject Information	
Question	**Response**
When I enter a recipient's DOB and Date of TXP, a pop up comes up showing "unable to locate on STARZL?	The Search Patients function on the Data Mart searches for patients utilizing only **one** of the four following data elements: Starzl Patient ID, Date of Birth, TRRID, Transplant Date. If more than one element is entered to the fields on the search bar, the site will send the "No patients matched your search criteria" message.
What if a patient is Transplanted twice. Do we enter data for the most recent one or the previous one?	All datapoints entered should correspond to appropriate TRR ID. Each transplant has a unique TRR ID, generating a unique set of operative and clinical forms. Please verify you are attributing the correct data to the unique TRR ID before submittal
Did we decide to limit study inclusion to specific years of transplant?	Yes, we have limited inclusion to transplants which occurred in 2002 going forward to align with the modern MELD/PELD era.

Perioperative Details Form	
Question	**Response**
Our center doesn't enter "graft weight"- Do I put "not done" as there are no other options or would you suggest leaving it blank.	If data is not available for a specified field, you can leave the field blank.
Does peri-operative time start from when anesthesia was given or when the patient entered the room till the patient left or when patient came out of anesthesia?	Calculate the operative time utilizing the surgery/incision start and end times. (not anesthesia start and end).

Form at Discharge from Transplant Admission	
Question	**Response**
In the discharge form: Date of discharge from ICU following transplant- our patients are in ICU and then they go to step down. Would it mean the entire stay from transplant to discharge or until they go to step down?	We would consider ICU time to be from OR to ICU. Remaining hospital time is considered to be stepdown, plus floor or all post formal ICU time.

Discharge form: Does this cover DC from hospital or ICU	This form should be completed at hospital DC or six weeks post-transplant, whichever is first.
The initial transplant ICU LOS did not calculate automatically after ICU discharge date was entered and form was saved.	This is not an automatically calculated field. It will require manual entry. Automatically calculated fields are greyed-out on the Data Mart.
A patient received FFP on multiple days post-transplant. Should those all be entered as separate events?	No, you can enter that as a single event. In situations like this, please utilize the comment box which appears when "Yes" is selected in the "Vascular Post-Op Event" box to record the range of days of the event.

Clinic Workflow Form 30 Day Follow-up Post Discharge	
Question	**Response**
For the 30-day post-transplant form, there are several questions asking about things that have occurred since the last visit (e.g., anticoag, pertinent imaging, biopsy) – Does this include things that have happened since discharge or since the transplant?	The 30-day follow-up post-transplant form is looking for data between the patient's ICU discharge date and 30 days post hospital discharge.
What if a patient is still hospitalized at 30 days post-transplant?	In this scenario, use data from the first clinic visit after discharge if discharge from ICU occurs more than 30 days post-transplant.
30 Day Form: Does this only cover DC from hospital to 30 days post-transplant	30 day follow up form should include data between hospital DC and 30 days post-transplant hospital DC. 6 Month form should include data between the 30 day follow up visit and 6 months post Tx.

Clinic Workflow Forms	
Question	**Response**
We have a patient that did not have a formal clinic visit at 6 mo. They had a clinic visit at 4 months and 10 months post-transplant. What is the acceptable window for entering data for the 6 month follow up form post-transplant?	Your 4-month clinic visit will suffice for this form as you may utilize clinical visit data within +/- 2 months.

What is the acceptable window for entering clinic follow up data for the 30 day follow up form?	Should include data between hospital discharge and 30 days post-transplant hospital discharge.
Annual follow-up (1-year, 2-year, 3-year, etc.): We had patients that were admitted or didn't have a clinic visit +/- 3 months of transplant anniversary. What is the acceptable window for entering data for clinic visits at the anniversary?	Utilize clinic visit data closest to the patients transplant anniversary
If we start data entry on a participant >1-year post-transplant, should we include only events in prior year, or everything from time of transplant to current?	The annual clinic forms begin at 1-year post-transplant. This is Visit 1. Visit 2 occurs approximately one year later. Data from Visit 1 will be entered into Form 1. Form 1 will reflect events which occurred since the last clinic visit recorded in the Data Mart. Data from Visit 2 will be entered into Form 2. Form 2 will reflect events which occurred since Visit 1. The subsequent data forms will follow in this same pattern.
What should we do if there isn't a liver transplant clinic visit in the visit window, but the patient has labs, active follow-up in other specialty clinics, with their PCP, or have an inpatient admission?	The best practice in this scenario is to enter any available data closest to the clinic date. This is true of all dates entered in the annual follow up forms. Enter the data from the data closest to the clinic date if a specific lab/procedure is done. If a specific lab/procedure wasn't done at a given clinic; values can be left blank. Admissions and ER visits are recorded as events on the follow-up forms as well.
"Pertinent imaging since last visit" – What does this mean?	This field is asking for any Ultrasound, MRCP, CT, PTC imaging. Selecting "Yes" will then make checkboxes with each of those options appear. Select all that apply, and then copy and paste the imaging report (excluding patient identifiers) into the textbox below the checkboxes.
When we saved the form, we got warnings for a long list of variables that were not options for me to enter.	This is a feature of the Data Mart. It is a Data Review function that you can choose to ignore. It is not an error message or a message signaling any incorrect entries. When a form is saved, a list of all possible variables and their new saved values are reported on the page.