

**OPTN Pediatric Transplantation Committee
Lost to Follow-Up & Transfers Workgroup
Meeting Summary
April 3, 2025
Conference Call**

**Rachel Engen, MD, Chair
Neha Bansal, MD, Vice Chair**

Introduction

The OPTN Pediatric Transplantation Committee's Lost to Follow-Up & Transfers Workgroup (the Workgroup) met via WebEx teleconference on 04/03/2025 to discuss the following agenda items:

1. Welcome
2. Project overview & Workgroup member introductions
3. Review of existing reporting process for lost to follow-up & transfers of care
4. Discuss & finalize data request

The following is a summary of the Workgroup's discussions.

1. Welcome

The Chair welcomed the Workgroup members.

2. Project overview & Workgroup member introductions

The Chair presented an overview of the project and invited the workgroup members to introduce themselves.

Data summary:

Project purpose:

- Standardize reporting of recipient loss to follow-up (LTFU) and transfers of care
 - Clarify transplant program responsibility for reporting LTFU & transfers of care to create more consistency in this data collection
- Better understand factors contributing to LTFU designation
 - LTFU designation stops the generation of transplant recipient follow-up forms, in turn, there is loss of critical data
 - Improve understanding of barriers to accessing post-transplant follow-up care
 - Age at transfer to adult care is of particular interest for pediatric recipients

Proposal:

- Changes to OPTN policy
 - Define transplant recipient LTFU as it applies to OPTN data submission requirements
 - Require transplant hospitals to report LTFU
 - Require transplant hospitals to report transfers of follow-up care
 - Why? To facilitate accurate recipient tracking and collection of age at transfers
- Changes to data collection

- Add data collection on factors contributing to LTFU reporting to the OPTN
 - Capture age at transfer of care
 - Create pathway for reporting transfer from pediatric to adult component at same OPTN institution

Changes would apply to pediatric and adult transplant recipients. Workgroup members include representatives from the OPTN Pediatric, Data Advisory, Transplant Administrators, and Transplant Coordinators Committees.

Summary of discussion:

No decisions were made.

Workgroup members introduced themselves. There were no questions or discussion on the project proposal or scope.

3. Review of existing reporting processes for lost to follow-up & transfers of care

The Workgroup reviewed an overview of the existing reporting processes for LTFU and transfers of care.

Data summary:

OPTN *Policy 18.1.B* requires transplant hospitals to submit *Organ Specific Transplant Recipient Follow-up (TRF)* 90 days after 6-month and annual anniversary of the transplant date until death or graft failure, or within 14 days of notification of recipient death/graft failure.

On adult and pediatric TRF, transplant hospital reports:

- Follow-up care provided by: Transplant center; Non Transplant Center Specialty Physician; Primary Care Physician; Other Specify [with text box]
- Date: Last Seen, Re-transplanted, or Death
- Patient Status: Living, Dead, Retransplanted, Not seen

Transplant centers may report recipient as LTFU via *Interim Report of Graft Failure, Death, or Lost* (Interim Report), if:

- Recipient is unlikely to return for follow-up visit
- Follow-up information cannot be obtained from another healthcare provider

Current data collection for Interim Report of LTFU

- Patient status date = one day after date last seen
- Graft status is not required
- **Proposed:** New data collection to provide insights on why recipient was LTFU

Reporting recipient LTFU stops annual generation of follow-up forms.

Summary of discussion:

4. Discuss & finalize data request

- OPTN Pediatric Transplantation Committee (Committee) discussed a formal data request for this project on March 6, 2025. The Committee recommended a data request to examine:
 - LTFU reporting by organ type, age at transplant, OPTN region
 - Utilization of options on Transplant Recipient Follow-up (TRF) form:
 - “Not Seen”

- Recommended during Data Advisory Committee check-in on 2/10/2025

Summary of discussion:

The Work Group discussed a formal data request to examine:

- LTFU for transplant recipients by recipient and transplant characteristics (organ type, age group, OPTN region, distance from recipient residence to transplant center, rurality/urbanicity, and primary payor)
- Patient transfers initiated by transplant program by accepting program response (accepted, rejected) and patients with no follow-up at accepting program
- Reported patient status on transplant recipient follow-up (TRF) forms
- Reported follow-up care provider on TRF forms
- Distribution of TRF forms with patient status reported as “not seen” for recipients reported as loss to follow-up
- For recipients with TRF forms with reported patient status as “not seen”, N (%) reported as LTFU after “not seen” reporting, and N (%) with completed TRF forms after “not seen” reporting

To inform their efforts on this project, the Workgroup discussed a formal data request to examine:

- LTFU for transplant recipients by recipient and transplant characteristics (organ type, age group, OPTN region, distance from recipient residence to transplant center, rurality/urbanicity, and primary payor)
- Patient transfers initiated by transplant program by accepting program response (accepted, rejected) and patients with no follow-up at accepting program
- Reported patient status on transplant recipient follow-up (TRF) forms
- Reported follow-up care provider on TRF forms
- Distribution of TRF forms with patient status reported as “not seen” for recipients reported as loss to follow-up
- For recipients with TRF forms with reported patient status as “not seen”, amount reported as LTFU after “not seen” reporting, and amount with completed TRF forms after “not seen” reporting

Workgroup members also discussed factors potentially contributing to transplant recipients being LTFU to the OPTN.

One factor is geographic relocation. Transplant recipients may move to a different area or state and require a transfer of care. A transplant recipient in the Workgroup reported that they encountered challenges in continuing post-transplant follow-up care at a transplant hospital when they moved to a different state; the recipient stated that a few different OPTN member institutions declined to accept them for follow-up care. It is unclear whether this is an isolated event.

Transitions from pediatric to adult care also present barriers. A Workgroup member reported that, anecdotally, some adult transplant programs decline to accept pediatric patients, particularly those with developmental delays, even when appropriate caregiving support is available. Additionally, even when clinical care is accepted, some programs may not assume responsibility for completing the required TRFs, creating further gaps in official tracking.

Financial considerations are another contributing factor. Pediatric recipients aging out of Medicaid or other state-based insurance programs may lose healthcare coverage. This loss can limit access to

essential services such as laboratory testing and clinic visits, particularly for patients living in rural areas. As a result, some patients may discontinue regular engagement with their transplant centers.

Administrative processes within the OPTN system may contribute to loss to follow-up as well. Transfers of care initiated in the OPTN portal may not always be formally accepted by the receiving transplant hospital. In these cases, it's possible for patients to fall into administrative gaps without either center maintaining ongoing follow-up obligations.

Patient choice also plays a role. Some recipients independently transition their follow-up care to non-transplant providers outside the OPTN system. While this may meet the clinical needs of the patient, it complicates the collection of follow-up data required for national transplant monitoring.

Language barriers and international relocation further complicate follow-up efforts. Patients for whom English is not the primary language may face additional challenges in navigating the healthcare system. Similarly, international recipients who return to their country of origin may become difficult to track through U.S.-based systems.

Finally, the lack of a standardized definition of LTFU across transplant programs creates inconsistency in reporting. Some centers may report a patient as lost based on a limited number of unsuccessful contact attempts, while others may use different thresholds. This variability complicates national efforts to accurately assess and address loss to follow-up across the transplant community.

Next steps:

OPTN Contractor staff will write up a formal data request on behalf of the Workgroup.

Upcoming Meetings

- TBD

Attendance

- **Workgroup Members**
 - Rachel Engen, Chair
 - Neha Bansal, Vice Chair
 - Rebecca Baranoff
 - Gertrude Okelezo
 - Ryan Fischer
 - Whitney Holland
 - Jill McCardel
 - Kati Robinson
 - Susan Stockemer
 - Katrina Fields
 - Jennifer Vittorio
 - Allen Wagner
 - Shawn West
- **HRSA Representatives**
 - N/A
- **SRTR Staff**
 - Avery Cook
- **UNOS Staff**
 - Betsy Gans
 - Dzhuliyana Handarova
 - Leah Nunez
 - Niyati Upadhyay
 - Kaitlin Swanner
 - Matt Cafarella
- **Other Attendees**
 - N/A