

**OPTN Pediatric Transplantation Committee
Lost to Follow-Up & Transfers Workgroup
Meeting Summary
July 24, 2025
Conference Call**

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

Introduction

The OPTN Pediatric Transplantation Committee's Lost to Follow-Up (LTFU) & Transfers Workgroup (the Workgroup) met via WebEx teleconference on 7/24/2025 to discuss the following agenda items:

1. Discuss LTFU definition/policy requirements
2. Discuss OPTN data collection on LTFU

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

1. Discuss LTFU definition/policy requirements

The Workgroup met to continue development of policy requirements related to Lost to Follow-up (LTFU) reporting.

Summary of discussion:

Decision #1: The Workgroup supported a dual-component framework to define in policy what constitutes LTFU to the OPTN:

- Transplant Recipient Follow-Up form (TRF) component: A certain number of TRFs submitted with a patient status of "Not Seen"
- Outreach Component: A certain number of failed outreach attempts

Decision #2: The Workgroup recommended requiring two distinct methods of contact be used to complete outreach attempts.

Timeline review

The meeting began with a review of the project timeline. The Workgroup aims to finalize policy language by Fall 2025, with the goal of submitting a proposal for public comment in Winter 2026. Proposed policy seeks to standardize LTFU reporting and clarify transplant program responsibilities, ultimately improving data consistency and utility across the OPTN system.

Review of Data Highlights

Members revisited data presented in the June meeting, which showed that LTFU rates increase over time, peaking at 12.6% at 15 years post-transplant. Percentage of recipients LTFU was highest among the following groups:

- By age at transplant: 18-34 (15.1%), 35-49 (15%), followed by 12-17 (13.2%)
- By organ type: Kidney (15.5%), Pancreas/Kidney-Pancreas (13.2%)
- By region: 5 (21.6%), 4 (17.3%), 9 (14.4%)

- By location: Higher for urban (13%) vs. Rural (10.2%)
- By insurance type: Other - self-pay, donation, free care, pending (19.8%), Unknown (17.8%)
 - Types included: Private, Medicaid, Medicare, Other public – CHIP, Dept. Of VA, etc., or Other – self-pay, etc.
- Distance from transplant hospital: 501+ nautical miles (27.8%); % LTFU increases as distance increases

The group noted that approximately 40% of patients reported as LTFU had no prior TRF forms marked “not seen,” while approximately 60% of those marked “not seen” once were later followed up.

Proposed framework for LTFU reporting

The Workgroup supported a dual-component framework to define what constitutes LTFU to the OPTN:

- Transplant Recipient Follow-Up form (TRF) component: A certain number of TRFs submitted with a patient status of “Not Seen”
- Outreach Component: A certain number of failed outreach attempts

The TRF component provides a clear indicator to support standardized LTFU reporting to the OPTN. Regarding the outreach component, the Workgroup felt required attempts to reach the transplant recipient would ensure there is consistent effort to follow recipients across transplant programs. Workgroup feedback indicated that some transplant programs may already be making such efforts.

Defining LTFU reporting criteria

The Workgroup considered how many “Not Seen” TRFs to include in the criteria to trigger required outreach attempts. The discussion emphasized three options:

- 1 “Not Seen” TRF
- 2 consecutive “Not Seen” TRFs
- An acceptable range of “Not Seen” TRFs, such as a minimum of 1 and maximum of 3

One member suggested including a range in policy to allow transplant hospital discretion over when to report LTFU, while others emphasized the need for standardization to avoid inconsistent reporting.

For the outreach component, the Workgroup discussed requiring 2 or 3 failed attempts over a specified period before LTFU is reported. There was also a discussion around requiring a minimum amount of time between attempts to ensure adequate time for the patient to respond before the LTFU determination. Members expressed a desire to balance thorough and consistent effort to follow recipients and the potential burden on transplant hospitals.

Members discussed the types of outreach that should be considered valid. While phone calls were supported as the most effective method, concerns were raised about patients with unstable contact information. Suggestions included allowing flexibility in outreach methods but requiring use of at least two distinct approaches (e.g., phone and electronic portal, or phone and mail).

The Workgroup acknowledged that requiring documentation of outreach attempts would increase administrative burden and would become an audit point. However, most agreed that such documentation is necessary to ensure accountability and consistency.

Additionally, members began to consider defining “successful” vs. “unsuccessful” outreach attempts.

Operational Considerations and Exceptions

The group explored whether certain organ groups, such as intestine transplant recipients, should be excluded from LTFU reporting due to unique follow-up challenges. No formal exclusions were decided. It

was agreed that the Workgroup must consider how to address LTFU after a transfer to non-OPTN providers.

There was also discussion about whether the definition should apply only after the first-year post-transplant. While most agreed that patients are unlikely to be lost within the first year, the group opted not to restrict the definition, allowing for flexibility in rare cases.

Next steps

The Workgroup will finalize proposed LTFU reporting criteria at an upcoming meeting.

2. Discuss OPTN data collection on LTFU

Due to time constraints, the Workgroup was unable to discuss data collection changes as planned. This item will be addressed at the upcoming meeting.

Upcoming Meetings

- August 28, 2025, 4-5 PM ET, teleconference

Attendance

- **Workgroup Members**
 - Rachel Engen
 - Neha Bansal
 - Rebecca Baranoff
 - Whitney Holland
 - Susan Stockemer
 - Allen Wagner
 - Shawn West
 - Roshan George
 - JoAnn Morey
- **HRSA Representatives**
 - N/A
- **SRTR Staff**
 - N/A
- **UNOS Staff**
 - Dzhuliyana Handarova
 - Leah Nunez
 - Niyati Upadhyay
 - Matt Cafarella
- **Other Attendees**
 - John Magee, OPTN President