OPTN Pediatric Transplantation Committee
Lost to Follow-up and Transfers Workgroup
Meeting Summary
June 26, 2025
Conference Call

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

Introduction

The Lost to Follow-up and Transfers Workgroup (the Workgroup) met via WebEx teleconference on 6/26/2025 to discuss the following agenda items:

1. Review and discuss LTFU data request results

The following is a summary of the Workgroup discussions.

1. Review and discuss LTFU data request results

During their April 3, 2025 meeting, the Workgroup received an overview of the project and finalized a data request to inform the development of a proposal that will include policy and data collection changes. Proposed changes will aim to standardize LTFU reporting to the OPTN and to help the transplant community better understand factors contributing to LTFU.

Data summary:

- % of recipients reported LTFU (overall)
  - 0.4% at 1-year follow-up
  - 1.1% at 2-year follow-up
  - 4% at 5-year follow-up
  - 8.9% at 10-year follow-up
  - 12.6% at 15-year follow-up
- Highest % LTFU at 15-year mark:
  - 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
- Follow-Up Care Provider Reported on TRF Forms by Follow-up Status[1]
  - Follow-up care provider on expected TRF forms was missing for a higher proportion of recipients who would later be reported as lost to follow-up

    - The majority of recipients in both groups were receiving follow-up care from their transplant hospital
- Distribution of TRF Forms with Recipient Status Reported as "Not Seen" by Recipient Follow-Up Status
    - For recipients who ended up being reported as lost, the number of TRF forms submitted with patient status "not seen" ranged from 0 to 7, with over 40% of recipients reported as lost having 0 TRF forms submitted with a patient status of "not seen" prior to lost to follow-up reporting
    - For recipients who ended up being reported as lost, the median number of TRFs with patient status "not seen" was 1
- Distribution of TRF Forms with Recipient Status Reported as "Not Seen" by Recipient Follow-Up Status and Age at Transplant
    - Pediatric recipients aged 0-11 at transplant were more likely to have multiple TRF forms reported as "not seen" before being reported as LTFU
        - Over 40% of recipients aged 0-11 had 3 or more "not seen" TRFs submitted prior to loss to follow-up reporting
    - Over 40% of older age groups had 0 TRF forms submitted as "not seen" prior to being reported LTFU
    - Most followed recipients (> 90%) had 0 TRF forms submitted with a "not seen" patient status
- Recipients Followed with a Completed Subsequent TRF Form after 'Not Seen' Reported on TRF Form[2]
    - Approximately 61% of recipients reported "not seen" on an expected TRF form were later seen and had a completed TRF form
- Electronic transfer requests[3]
    - Over 7,000 electronic transfers were initiated since mid-2017
    - 63.8% of initiated transfer requests were accepted by the receiving program
    - 23.3% of initiated transfer requests expired[4]
    - 97.8% of patients with accepted transfers were seen at the accepting program

Summary of discussion:

No decisions were made.

Several members flagged the high rate of expired transfers as unacceptable. One workgroup member noted that the 23% expiration rate was high and suggested that more proactive measures should be considered, such as automatic emails to administrators or alerts to encourage a response. They shared their personal experience submitting transfer requests that often expire without action and emphasized how frustrating and inefficient the process can be.

This prompted agreement from other members, who echoed similar concerns. Another workgroup member offered a real-world example where a lack of awareness had stalled transfers—her team only succeeded in transferring over 25 patients once she directly contacted a quality manager at another transplant hospital. This led to a broader recognition that communication breakdowns between initiating and receiving centers are a barrier, often due to differences in who manages electronic systems within transplant centers. Some participants suggested that clinical coordinators may complete

verbal handoffs, but if administrative staff are unaware or unfamiliar with the electronic transfer tools, the transfer isn't finalized in the OPTN Data System, resulting in expired requests and loss of data continuity.

Participants agreed that programming solutions could support these workflows. One workgroup member suggested that the OPTN Data System should adopt a function similar to other modules—like the one used for tracking extra vessels—where the system automatically alerts centers if a transfer request remains unaddressed after a specific timeframe, such as 21 or 30 days. Another member added that alerts should be sent to both sending and receiving centers—one notifying that a transfer has expired and the other that no action was taken. These ideas were marked as an area for future exploration.

The conversation then shifted to defining what constitutes a recipient "lost to follow-up." Several members affirmed that this should remain a primary goal of the workgroup. One workgroup member raised a nuanced point: many patients currently marked as LTFU are not lost in the clinical sense but rather have transferred care to a non-OPTN provider or an international center. In these cases, the transplant center may be unable to formally transfer the patient, resulting in a default LTFU classification. Multiple members suggested the system should include a clearer way to distinguish between actual disengagement in care and transfers to non-OPTN providers, perhaps through additional data collection or specific designation.

The group began exploring whether a time-based standard should be a core element of the LTFU definition. One workgroup member advocated for a one-year threshold, noting that if a patient has not been seen in a year, particularly post-transplant, it is no longer medically appropriate to prescribe immunosuppressive medications. Another agreed and emphasized that a one-year time frame would provide consistency across centers.

However, another workgroup member shared their hospital's approach, which uses three failed contact attempts—typically spaced out over a month—before designating a patient as LTFU, with oversight from a manager. This generated concern from others that such discretion can lead to inconsistent designations. One member pointed out the potential for misuse or confusion, especially when contact attempts are carried out too quickly due to staff turnover or misinterpretation of protocols.

As the discussion progressed, several members raised the idea of developing a multi-factor definition—one that includes a time threshold, the number of "not seen" TRFs, and possibly failed contact attempts. Another member pointed out the risk of either extreme: some patients are reported as LTFU with no prior "not seen" TRFs, while others accumulate multiple "not seen" forms over several years without being formally marked as lost. This inconsistency underscores the need for standardized criteria in OPTN policy.

The group also revisited the issue of data gaps and documentation. For example, while the data suggested there may not be large differences in LTFU percentages by insurance type, multiple members noted that insurance data is only collected through year five on TRF forms. One member suggested that loss of insurance may be a significant but undocumented factor. There was agreement that data collection on reasons a recipient is LTFU would be helpful to the transplant community. Suggested reasons could include insurance loss, patient relocation, refusal of care, or transfer to a non-OPTN provider.

Upcoming Meeting

- July 24, 2025, 4-5PM ET, teleconference

Attendance

- **Workgroup Members**
  - Rachel Engen
  - Neha Bansal
  - Susan Stockemer
  - Shawn West
  - Jennifer Vittorio
  - Ryan Fischer
  - Allen Wagner
  - Jill McCardel
  - Katrina Fields
  - Roshan George
  - Whitney Holland
- **SRTR Representatives**
  - Avery Cook
- **UNOS Staff**
  - Leah Nunez
  - Matt Cafarella
  - Dzhuliyana Handarova
  - Niyati Upadhyay
  - Laura Schmitt
  - Lauren Mooney