

OPTN Pediatric Transplantation Committee
Lost to Follow-up and Transfers Workgroup
Meeting Summary
September 25, 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 9/25/2025 to discuss the following agenda items:

1. Discuss policy requirements related to lost to follow-up reporting
2. Discuss proposed data collection on LTFU transplant recipients

The following is a summary of the Workgroup discussions.

1. Discuss policy requirements related to lost to follow-up reporting

The Workgroup met to continue discussing proposed policy criteria for reporting transplant recipients as lost to follow-up (LTFU).

Summary of discussion:

The Workgroup decided to proceed with its recommendations to propose outreach specifications as policy requirements, as opposed to formal guidance.

The Workgroup revisited prior recommendations, which included requiring at least one “not seen” Transplant Recipient Follow-up (TRF) form and three failed outreach attempts using two distinct contact methods, with the first and third attempts spaced at least 150 days apart and a 30-day waiting period after the final attempt before reporting. Members affirmed their earlier recommendation to propose these outreach specifications as enforceable policy requirements, as opposed to recommendations or formal guidance, to ensure transplant programs make reasonable efforts before reporting a patient as lost.

The discussion then focused on policy language options. Some members supported framing the language to clarify that programs may report a patient as lost only if minimum criteria are met, rather than mandating reporting in all cases. This approach allows flexibility for programs that wish to continue receiving follow-up forms in their expected queue as they try to re-engage the patient, without penalty. The Workgroup also agreed that policy should accommodate exceptional cases where early reporting is appropriate, such as when a recipient explicitly declines follow-up care. To address such scenarios, there was some support for including language that permits reporting when the recipient is “unlikely to return,” while acknowledging the need for supporting documentation, such as an FAQ, to reduce ambiguity. Several members suggested providing examples of acceptable contact methods, developing FAQs or reference materials to clarify when “unlikely to return” applies, and ensuring policy language avoids confusing double negatives. There was also discussion about aligning outreach timelines with

other OPTN policies and including accountability measures without discouraging programs from maintaining contact beyond minimum requirements.

Next steps

The Workgroup will refine proposed policy requirements related to reporting transplant recipients as lost to follow-up.

2. Discuss proposed data collection on LTFU transplant recipients

The Workgroup had a brief discussion about proposed data collection on factors contributing to LTFU designations in the OPTN Data System.

Summary of discussion

The Workgroup acknowledged that defining reasons for loss to follow-up may be challenging. Members emphasized the importance of structured response options and a desire to avoid free-text fields to improve data usability and avoid vague categories such as “other”, if possible. They also noted that reasons should capture scenarios like loss of insurance or issues during transfers, which could inform future policy and advocacy efforts. Concerns were raised about balancing specificity with practicality and ensuring data collection does not create undue burden for transplant hospitals. The Workgroup agreed to revisit this topic in the next meeting and consider how often programs know the reasons for loss and how reliably this information can be obtained.

Next steps

During an upcoming meeting, the Workgroup will discuss: proposed data collection on why a recipient is lost to OPTN follow-up; how to address expired electronic transfer requests in the OPTN system; and proposed data collection on pediatric recipient transfers to adult care.

Upcoming Meeting

- December 4, 2025, 3-4:30p.m. ET, teleconference

Attendance

- **Workgroup Members**
 - Neha Bansal
 - Susan Stockemer
 - Shawn West
 - Katrina Fields
 - Roshan George
 - Whitney Holland
 - JoAnn Morey
 - Rebecca Baranoff
 - Katherine Robinson
- **SRTR Representatives**
 - Avery Cook
- **UNOS Staff**
 - Leah Nunez
 - Matt Cafarella
 - Tory Boffo