

OPTN Pediatric Transplantation Committee

Meeting Summary

June 26, 2024

Conference Call

Emily Perito, MD, Chair

Rachel Engen, MD, Vice Chair

Introduction

The Pediatric Transplantation Committee (Committee) met via WebEx teleconference on 6/26/2024 to discuss the following agenda items:

1. Pediatric Loss to Follow up discussion
2. Open Forum

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

1. Project Idea: Pediatric Loss to Follow up

On December 13, 2023 and February 2, 2024, the Committee reviewed data and discussed the issue of recipient loss to follow up (LTF) during the course of transplant follow up care. Pediatric recipients may be particularly vulnerable to LTF during the transition and transfer from pediatric to adult care. A recipient may be designated as lost to follow up in the OPTN Computer System because of transfer to a non-OPTN provider; loss of contact; recipient not being under provider care. Current data collection lacks granularity, making it difficult to understand the scope of the problem. The Committee has discussed project ideas to address pediatric LTF including data collection opportunities to inform potential solutions.

On May 15, 2024, the Committee confirmed interest in pursuing a project related to pediatric LTF. Project ideas to date are:

- Establishing a formal definition for loss to follow up
- Re-introducing data collection "transfers to non-OPTN center"
- Updating transplant program codes to distinguish pediatric programs from adult programs at the same hospital

Summary of discussion:

No decisions were made.

OPTN [Policy 18.1.B](#) requires transplant hospitals to submit *Organ Specific Transplant Recipient Follow-up* (TRF) forms for each of their recipients. TRF forms are submitted 90 days after 6-month and annual anniversary of the transplant date until death or graft failure and within 14 days of notification of recipient death/graft failure. There is an option on the TRF forms for patient status, which included a drop-down option for "transfer to non-OPTN provider" until May 2023; the option was removed as non-OPTN centers not expected to share patient data with the OPTN. Currently there is no limit to the number of times transplant programs can report patient status as "not seen". Help documentation

states a recipient may be reported LTF via the Interim Reporting Form (IRF); transplant programs are advised to enter the date one day after the patient was last seen in the Patient Status Date field.

The Committee discussed an option to add data collection to the IRF to capture the reason for LTF. To initiate the discussion, members considered whether the following options would be applicable and provide valuable information: transfer to non-OPTN provider (i.e. Cannot obtain data); unable to contact; maximum age reached. The ability to report transfers to non-OPTN providers on the IRF would help the community discern recipients receiving medical care from those that are not. Some members commented that their pediatric transplant programs do not enforce a maximum age if a patient has no other care options, so that option may not be applicable. The importance of understanding whether there are inequities in access to care by financial/insurance status was highlighted. Members were concerned that this effort would not address the need for more long-term outcomes data; the limitations to obtaining these data were acknowledged. Interest in capturing the transfer from pediatric to adult care within the same facility was reiterated.

There was division among members on whether to focus on data collection or a white paper, with concerns about the effectiveness and impact of both approaches. Some suggested a white paper to further analyze the issue may be appropriate. Members reported that transplant program practices surrounding the transition of care may vary widely; some felt obtaining community feedback on these practices may be helpful in identifying future initiatives to improve post-transplant outcomes and reduce LTF. Other members were supportive of moving forward with a project to make changes within the OPTN Computer System.

Next steps:

The Committee will continue to discuss this project idea at upcoming meetings.

2. Open Forum

There were no open forum speakers.

Upcoming Meetings

- July 25, 2024, 4 PM ET, conference call

Attendance

- **Committee Members**
 - Emily Perito
 - Rachel Engen
 - Neha Bansal
 - Aaron Wightman
 - Caitlin Peterson
 - Dan Carratturo
 - Geoff Kurland
 - JoAnn Morey
 - Jodi Smith
 - Sonya Kirmani
 - Meelie DebRoy
 - Melissa McQueen
 - Reem Raafat
 - Ryan Fischer
 - Shawn West
 - Daniel Ranch
- **HRSA Representatives**
 - James Bowman
 - Marilyn Levi
- **SRTR Staff**
 - Avery Cook
- **UNOS Staff**
 - Leah Nunez
 - Susan Tlusty
 - Betsy Gans
 - Laura Schmitt
 - Dzhuliyana Handarova
- **Other attendees**
 - Roshan George (visiting community member)