

OPTN Pediatric Transplantation Committee

Meeting Summary

October 24, 2024

Conference Call

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

Introduction

The Pediatric Transplantation Committee met via WebEx teleconference on 10/24/2024 to discuss the following agenda items:

1. Project Idea: Pediatric Loss to Follow-up
2. Open Forum

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

1. Project Idea: Pediatric Loss to Follow-up

The Committee's project idea to address problems related to pediatric loss to follow-up (LTF), transition/transfer from pediatric care to adult care was last discussed during the in-person meeting on September 17, 2024. The Committee was supportive of pursuing a project related to LTF and improving graft outcomes that may involve: a formal definition of recipient LTF; collecting data on the reason(s) a recipient was LTF; collecting data on transfers from pediatric to adult care.

Summary of discussion:

The Committee determined data collection on transfer refusals and changes to data fields regarding patient status (e.g. cognitive development, etc.) would be out of scope for this project proposal.

There was a brief review of past Committee work related to pediatric LTF and transfers of care, including the OPTN Guidance Document on Pediatric Transitions and Transfers, which members were asked to review. Insights from analyses incorporated into the guidance document were reviewed. Additionally, a draft project purpose statement was discussed.

The Committee determined data collection on transfer refusals and changes to data fields regarding patient status (e.g. cognitive development, etc.) on transplant recipient follow-up (TRF) forms would be out of scope for this project proposal. There was no data or evidence readily available to show that transfer refusals or data burden related to the TRF are factors contributing to pediatric recipient LTF.

There was some discussion surrounding the utility of capturing when the transfer to adult care occurs and at what age the transfer occurred. There is a need to further evaluate this potential proposal component and how it may fit into this project proposal.

Next steps:

The Committee will continue to discuss and refine the project idea prior to initial reviews by the OPTN Data Advisory Committee and Policy Oversight Committee.

2. Open Forum

There were no open forum speakers.

Upcoming Meeting

- November 21, 2024, teleconference, 4-5 PM ET

Attendance

- **Committee Members**
 - Neha Bansal
 - Aaron Wightman
 - Gonzalo Wallis
 - Jennifer Vittorio
 - JoAnn Morey
 - Sonya Kirmani
 - Meelie Debroy
 - Daniel Ranch
 - Shawn West
 - Katrina Fields
 - Jill McCardel
- **HRSA Representatives**
 - James Bowman
- **UNOS Staff**
 - Leah Nunez
 - Kaitlin Swanner
 - Dzhuliyana Handarova
 - Susan Tlusty
 - Laura Schmitt
 - Betsy Gans
 - Niyati Upadhyay