OPTN Heart Transplantation Committee
Meeting Summary
November 19, 2024
Conference Call

J.D. Menteer, MD, Chair
Hannah Copeland, MD, Vice Chair

Introduction

The OPTN Heart Transplantation Committee (Committee) met via WebEx teleconference on 11/19/2024 to discuss the following agenda items:

1. Welcome, introductions, and agenda review
2. Waiting Time Attribute
3. Open Forum
4. Closing remarks

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

1. Welcome, introductions, and agenda review

The Chair welcomed the members and provided an overview of the agenda. Members calling in by phone only were reminded to tell OPTN contractor staff their names for attendance purposes. Non-committee members and those without business before the Committee were reminded that they should follow the proceedings using vimeo.com/optn.

2. Waiting Time Attribute

The Chair provided the Committee members with an overview of the proposed Waiting Time attribute and rating scale.

Data summary:

The objective of this presentation is to describe how waiting time is used in current allocation policy as well as provide an overview of how the Committee plans to address waiting time in continuous distribution (CD). In CD, the current medical urgency statuses for adult and pediatric candidates will be merged in a single rating scale. Medical urgency will be a major source of priority points in determining allocation of a given donor to a candidate. Other attributes will also grant priority points (for example, blood group, pediatric age group, sensitization, travel efficiency).

The Chair reminded members that in early 2024, the OPTN Continuous Distribution Pediatric Waiting Time Workgroup (Workgroup) reassembled, including some new and old members from last year, to tackle the problem of developing a pediatric waiting time system. The Workgroup consisted of OPTN Heart Committee members, OPTN Pediatric Committee members, and individuals associated with the OPTN and the Pediatric Heart Transplant Society. It was mentioned that pediatric patients who are smaller than the smallest adult donors can have exceptionally long waiting times. The Chair said that not including waiting time in CD could have disastrous effects on pediatric patients, especially when the Committee provides separate amounts of priority points to the five criteria currently captured within pediatric status 1A.

Proposal:

- Points will be awarded to recipients over time
- Points will be under the access to care goal within CD
- Time cannot be the only parameter. Must include proportion to urgency
- If urgency has a range of 100 points, and all former 1A situations yield between 60 and 100 points, then the Workgroup agreed that 18 months at 60 points should yield between 15 and 20 points
- Patients who move from high urgency downward (an atypical situation) would get less urgency points but still receive waiting time points unchanged

Summary of discussion:

OPTN Heart Transplantation Committee did not make any decisions.

A member asked whether the proposal would add medical urgency points and if that should be considered a separate attribute. The Chair explained that waiting time would be categorized under the Patient Access goal and clarified that the proposed Waiting Time for LVAD (Left Ventricular Assist Device) would also fall under the Medical Urgency goal. The Chair clarified that something being weighted for, say, 15 points, is referring to 15% of the total rating scale of that attribute. The medical urgency attribute and the separate waiting time attribute will be distinct from each other. For this discussion, it is important to consider one scale, which was normalized to the urgency scale. When indicating that a candidate earned 15 points, it means 15 points of medical urgency, but it will exist within a separate bucket. This bucket may be sized at 40 points, but once scaled to a 100-point system, medical urgency would represent 40% of the total score, while access to care might only account for 17%.

Another member clarified that this method allows for credit to be given for waiting time, emphasizing that higher medical urgency would earn more points, but this would reside in a distinct attribute. Some organs, like lungs, do not account for waiting time at all; they have not included it in their scoring for a long time. However, waiting time has always been considered in heart allocation. This distinction aims to provide recognition for being on the waiting list, which is particularly significant for pediatric patients.

Another member inquired if the discussion was limited to adding points for waiting time for pediatric patients or if this applied to adult patients on LVAD as well. The Chair noted that the proposal is intended more broadly. However, if a patient has low urgency, they will not accumulate many points; for instance, someone on List A with a medical urgency score of 20 for a decade might only accumulate a handful of points. A member raised a concern regarding patients in higher urgency situations who accumulate a lot of waiting time points. If such a patient later drops to a lower urgency, could they accumulate enough points to surpass someone who is currently an inpatient and; therefore, likely to have a higher priority? The Chair confirmed that this is a possibility. The same member pointed out that there must be a decision on how much weight to assign to waiting time. If it is categorized as a separate attribute, it will stand alone, with a potential weight of 10% or 20% of the final score, while medical urgency constitutes 40%. Within CD, there could be scenarios where a patient overtakes others based on how weights are applied—something that is currently restricted by specific classifications. The Chair noted that everything will start to align as the Committee further develops its understanding of how the attributes and rating scales will come together as they develop the composite allocation score. The Committee is relatively close to being able to present a theoretical structure for the complete continuous distribution system in the next two or three meetings, which will be beneficial. SRTR staff

asked whether the waiting time points relate to the 100 possible points for urgency and not the 100 possible points for all continuous allocation scores. The Chair confirmed this was correct.

A member pointed out that candidates can be assigned to the 'inactive' status and wondered how such time would be accounted for within the rating scale. The member also pointed out that oftentimes, candidates are unaware that they have been assigned to the inactive status. As a result, such candidates are likely to think they have much more waiting time accrued then they actually do within the allocation system.

The members agreed that modeling and data analysis will be very important when it comes to understanding how the proposed waiting time rating scale functions.

Next steps:

The Committee will continue finalizing the Waiting Time attribute and rating scale along with the other attributes and rating scales.

3. Open Forum

There were no requests to speak during this part of the meeting.

4. Closing remarks

Public Comment for the Committee's *Escalation of Status for Time on LVAD* proposal will occur starting in January 2025. The Committee's regional representatives will present their proposal at each regional meeting. OPTN contractor staff will be scheduling prep sessions with the regional representatives to review the presentation. The Chair thanked the members for attending and advised that the 12/04/2024 meeting is cancelled.

Upcoming Meetings

- ~~July 2, 2024 from 4:00 to 5:30 pm~~
- ~~July 16, 2024 from 5:00 to 6:00 pm~~
- ~~August 7, 2024 from 4:00 to 5:00 pm~~
- ~~August 20, 2024 from 5:00 to 6:00 pm~~
- ~~September 4, 2024 from 4:00 to 5:00 pm~~
- ~~September 17, 2024 from 5:00 to 6:00 pm~~
- ~~October 2, 2024 from 4:00 to 5:00 pm~~
- ~~October 9, 2024 from 9:00 am to 4:00 pm (In-person meeting, Detroit, MI)~~
- ~~October 15, 2024 from 5:00 to 6:00 pm~~
- ~~November 6, 2024 from 4:00 to 5:00 pm~~
- ~~November 19, 2024 from 5:00 to 6:00 pm~~
- December 17, 2024 from 5:00 to 6:00 pm
- January 1, 2025 from 4:00 to 5:00 pm
- January 21, 2025 from 5:00 to 6:00 pm
- February 5, 2025 from 4:00 to 5:00 pm
- February 18, 2025 from 5:00 to 6:00 pm
- March 5, 2025 from 4:00 to 5:00 pm
- March 18, 2025 from 5:00 to 6:00 pm
- April 2, 2025 from 4:00 to 5:00 pm
- April 15, 2025 from 5:00 to 6:00 pm
- May 7, 2025 from 4:00 to 5:00 pm
- May 20, 2025 from 5:00 to 6:00 pm

- June 4, 2025 from 4:00 to 5:00 pm
- June 17, 2025 from 5:00 to 6:00 pm

Attendance

- **Committee Members**
  - J.D. Menteer
  - Hannah Copeland
  - Denise Abbey
  - Tamas Alexy
  - Maria Avila
  - Kevin Daly
  - Rocky Daly
  - Jill Gelow
  - Timothy Gong
  - Eman Hamad
  - Jennifer Hartman
  - Earl Lovell
  - Cindy Martin
  - Mandy Nathan
  - Jason Smith
  - David Sutcliffe
  - Martha Tankersley
  - Dmitry Yaranov
- **HRSA Representatives**
  - None
- **SRTR Staff**
  - Yoon Son Ahn
  - Katie Audette
  - Monica Colvin
  - Grace Lyden
- **UNOS Staff**
  - Keighly Bradbrook
  - Viktoria Filatova
  - Cole Fox
  - Katrina Gauntt
  - Kelsi Lindblad
  - Eric Messick
  - Holly Sobczak
  - Kaitlin Swanner
  - Sara Rose Wells
- **Other Attendees**
  - Shelley Hall
  - Ted Papalexopoulos