

Meeting Summary

OPTN Continuous Distribution Workgroup Meeting Summary December 19, 2019 Conference Call

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Introduction

The Continuous Distribution of Lungs Workgroup met via Citrix GoTo teleconference on 12/19/2019 to discuss the following agenda items:

- 1. Summary of Attribute Decisions
- 2. Continuous Distribution Definitions and Expectations for Workgroup
- 3. Finalize Travel Cost Data Request

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

1. Summary of Attribute Decisions

The Workgroup reviewed the decisions made thus far regarding the attributes to include in a new continuous distribution system.

Summary of discussion:

During the discussion, a Workgroup member asked whether giving priority to all candidates less than 18 years would negatively impact the waitlist mortality of adult transplant programs where both an adult and pediatric program exist. For example, transplant programs may be penalized because they have higher adult waitlist mortality. Another member clarified that this had been assessed previously when the last revisions were made to the LAS, and that in general, there was really no impact on adult waitlist mortality based upon the modeling results produced at that time. Furthermore, because the pediatric lung population is so small, there doesn't seem to be any impact. SRTR staff said they would try to find the paper written at the time addressing the topic. (The paper was Tsuang, et al, "Broader Geographic Sharing of Pediatric Donor Lungs Improves Pediatric Access to Transplant," *American Journal of Transplantation* 2016; 16: 930-937.) One Workgroup member commented that they were not sure it is absolutely necessary to give pediatric candidates access to all donors in the country, because programs will tend not to give them lungs from older adults.

One Workgroup member asked whether ischemic time was really that important to include in a composite score. Another member stated that the travel efficiency is the most important travel component, and that ischemic time is less important until you get out to 6-8 hours. As such, this member supported leaving ischemic time in there, and then determining how to calculate it into the post-transplant survival.

Another Workgroup member asked whether they should consider a program's logistic and personnel costs. Clarification was provided that the Workgroup had previously had this conversation about placement efficiency and system efficiency. At that time, the Workgroup decided that "cost" was the only concept a rating scale could be developed for.

2. Continuous Distribution Definitions and Expectations for Workgroup

UNOS staff presented the definitions to be used during the AHP training next Spring 2020. The definitions for considerations consisted of:

- Goal of the project (allocation of deceased lungs)
- Medical urgency
- Post-transplant survival
- Reducing biological disadvantages in transplant access
- Prior living donor
- Pediatric age group priority
- Travel efficiency

Summary of discussion:

A Workgroup member asked whether the definitions were meant for the general public. Clarification was provided that the definitions were for both laypersons and professionals, because the Decisions Lens activity will be available to patients and their families, as well as transplant professionals. In that case, members suggested including an intro paragraph about NOTA and the Final Rule for the general public to read and understand. UNOS staff will take this into consideration, and will be providing training to all participants of the AHP exercise, including education on NOTA and the Final Rule. Another Workgroup member stated when considering the proposed Travel Efficiency definition, they interpreted the phrase "shipping the organ will cost less" to mean that the OPTN would be trying to find the candidate for whom it is cheapest to fly an organ. Suggestions to modify this sentence included putting the phrase "all else equal" or "give priority to". Members supported using a different term and being more explicit about which component of the system will be prioritized, because they do not want programs to travel far distances for minimally significant patient outcomes.

Next steps:

UNOS staff will modify the AHP definitions based on the Workgroup's feedback and suggestions.

3. Finalize Travel Cost Data Request

The Workgroup discussed how to construct a rating scale for measuring travel cost, and finalizing a data request for SRTR related to this.

Summary of discussion:

The Workgroup had an in-depth discussion about OPO costs. Many Workgroup members felt that OPO acquisition fees should be included in the calculation. However, the OPTN does not systematically collect cost data; and therefore, cannot incorporated acquisition fees. Also, other members pointed out that these OPO acquisition costs may not be consistent across the country. One member noted that there are astronomical differences in acquisition fees (\$20,000 vs. \$60,000 to procure a lung). An SRTR member opined that even though OPOs have different costs associated with them, this would not change the costs overall (Why?). Furthermore, going a longer distance does not necessarily increase costs because of the fee variance (How does this work?). Workgroup members supported someday including these OPO costs as this may promote transparency.

In terms of the SRTR data request, SRTR's impression was that the Workgroup wanted a mapping of per mile cost. One Workgroup member opined that mileage may not differ that much when you are flying. Another member stated that it is dollars per time that should be evaluated, along with organ acquisition

fees. For example, you could drive to the most expensive OPO or you could fly to it. Clarification was provided that the OPTN is not trying to incorporate OPO cost differentials but rather trying to determine overall costs. One Workgroup member asked whether data from stand along OPOs (independent OPOs with their own donor procurement center) could be excluded from the analysis. However, it is not known whether these donor procurement centers do pediatric lung transplants. Also, few such centers exist in the U.S. SRTR staff clarified that they are not accounting for the use of such centers. Instead, their analysis uses just donor hospital to recipient hospital. In response, a Workgroup member stated that the SRTR's analysis then will be skewed. SRTR acknowledged that this could be true because the procurement centers would not be included, and that this could be a limitation. SRTR stated that in theory you could exclude them, but doing so would require a more thorough understanding of the potential implications. UNOS staff clarified that other organ committees have spoken about this, but that they agreed for now to use distance to donor hospital.

Workgroup members supported exploring other sources of data for OPO costs. A suggestion was made to reach out to AOPO. For now, the SRTR will move forward with the data request as initially proposed.

Upcoming Meetings

- January 8, 2020
- January 9, 2020
- January 15, 2020
- January 16, 2020