

**OPTN Continuous Distribution Workgroup  
Meeting Summary  
December 11, 2019  
Conference Call**

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## **Introduction**

The Continuous Distribution of Lungs Workgroup met via Citrix GoTo teleconference on 12/11/2019 to discuss the following agenda items:

1. Continuous Distribution: Waiting time and candidate age

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

### **1. Continuous Distribution Waiting time and candidate age**

The Workgroup continued their discussion regarding factors to include in the continuous distribution system, including waiting time, and a candidate age.

#### Summary of discussion:

##### Waiting time

Previously, some members had indicated that waiting time should not receive much priority. It was noted that waiting time is functionally used to distinguish between pediatric candidates and some exception candidates. Also, it had been discussed the administrative need for a tiebreaker. When a review of literature and previous Committee materials was conducted, it was found that these materials focused on how much weight should be placed on waiting time versus other attributes like medical urgency.

During this meeting's discussion, a member noted that waiting time has to do with issues in determining a candidate's medical priority. For example, there may be pediatric candidates with different waitlist mortalities grouped together, and that waiting time is used to distinguish between them. In this case, it is inferred that candidates with longer waiting times may not live much longer than those with shorter waiting times. At the same time, if a candidate is becoming sicker, then their LAS should be getting worse, and therefore their access should be increasing. As such, a member supported including waiting time as a factor, but not placing much weight on it. Another member supported this position, but was concerned that candidates may be listed earlier if transplant programs saw an advantage of having a longer waiting time. Furthermore, this member stated that prioritizing waiting time may increase the administrative burden on transplant programs because there are so many factors that impact listing practices.

A suggestion was made to not include waiting time as an attribute, but rather use it as a tiebreaker. Clarification was provided that this could be done, but that there was concern this could make an unjust system. However, Workgroup members stated that in their view, adopting waiting time as a tiebreaker would not be unjust, especially since data has shown that candidates with longer waiting times typically have lower LAS scores. In the end, the Workgroup unanimously supported to not include waiting time as an attribute to be weighted. Rather, the new system will continue to use it as a tie-breaker.

An SRTR member noted that from society's perspective, candidates who have waited longer should be given more priority. As such, members supported revisiting this attribute in the future based on public comment feedback.

### Candidate age

At the October Thoracic in-person meeting, the committee had discussed the desire to maintain a preference for pediatric candidates similar to how it occurs in current policy. Some members had agreed to group candidates aged 0-18 together and not pursue age matching, while some other members also wanted to prioritize candidates aged 12-17 for adult donors.

During today's meeting, the Workgroup was asked to consider two questions. First, should candidates be grouped as: 1) 0-18 and  $\geq 18$ , or 2) 0-11, 12-17, and  $\geq 18$ ? Second, should candidates be prioritized, based upon candidate age, for adult ( $\geq 18$ ) vs. pediatric ( $< 18$ ) donor lungs?

Members were reminded of several items for consideration. For example, there are legal restrictions / conditions governing the use of age in healthcare, that generally prevent the use of age when determining who receives benefits. At the same time, NOTA contains a statutory provision allowing the special circumstances of pediatrics to be considered in policy-making. However, the provisions speaks of "pediatrics" not a specific subset of those under 18 years of age. In addition, the Workgroup would need to provide a clinical reason or reasons why candidates should be grouped in categories other than 18 or younger.

A member stated that it made the most sense to divide the candidates' age into two categories (0-18 and  $\geq 18$ ), and to prioritize candidates under 18 years of age. The member viewed the use of two categories to be most aligned with NOTA and the Final Rule, as opposed to three categories. The member suggested that three categories seems to create a hard boundary that does not need to be in policy. For example, should a 12-year old candidate have priority over a 13-year old candidate, if all of their other characteristics are the same? It does not seem like it.

Another member asked about how the prioritization would work since LAS is not used for candidates younger than 12 years old, and how would it impact the weighting of the attributes. Right now, the classification based system separates these two types of candidates. The Workgroup previously discussed how to score the candidates' medical urgency and post-transplant survival so that the candidates can be compared in a points based system.

After discussing the first question about how should candidates be grouped, the Workgroup chose the option of grouping candidates as either 0-18 or  $\geq 18$ .

The Workgroup moved on to discussing the second question, should candidates be prioritized, based upon candidate age, for adult ( $\geq 18$ ) vs. pediatric ( $< 18$ ) donor lungs? In current policy, pediatric candidates are prioritized for pediatric donors while adolescent and adult candidates are prioritized for adult donors. SRTR staff provided some information about the number of candidates aged 0-11 and 12 to 17 on the waiting list compared to other age groups. Information was also discussed regarding the lung transplant rates for these age groups. The Workgroup members discussed the data and findings in the context of the OPTN Principles of Pediatric Allocation. After discussing the second question, the Workgroup chose to prioritize pediatric candidates ( $< 18$  years old) for all donors.

### Next steps:

At the next meeting, Workgroup members will be asked to discuss the criteria definitions created for the AHP exercise. Members will also be provided with a recap of the attributes they have already worked through.

### **Upcoming Meetings**

- December 12
- December 19