

OPTN Continuous Distribution of Lungs Workgroup

Meeting Minutes

September 19, 2019

Conference Call

Erika Lease, MD, Vice Chair

Rocky Daly, MD, Subcommittee Chair

Introduction

The Continuous Distribution of Lungs Workgroup met via Citrix GoTo teleconference on 09/19/2019 to discuss the following agenda items:

1. Updating the Lung Allocation Score (LAS) Cohort
2. Fall 2019 Public Comment: Update

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

1. Updating the Lung Allocation Score (LAS) Cohort

UNOS staff began the discussion on determining the frequency of regular LAS cohort updates, the most effective way to notify the community about any potential LAS updates, and which potential data elements for inclusion in the LAS.

Summary of discussion:

To begin, one Workgroup member was concerned about the resources and data burden for the OPTN and SRTR. Clarification was given that updating the LAS should not interfere with PSRs, though the burden would not be necessarily light. It was also noted that once the LAS cohort is initially updated, the Workgroup might have a better sense of how frequently the cohort would need to be updated. For example, if there is not much change, then the cohort may not need to be updated but once every 2 or 3 years. SRTR commented that updating the cohort every 6 months may be too frequent, because the cohorts would not be expected to change that much within the span of 6 months. A Workgroup member commented that changes to the LAS are usually not monitored until a year after implementation, so a more reasonable timeline may be every 2 to 3 years.

Next, discussion began around revising the LAS, including improving the data collected and adding new data elements. Since there is concern about this project hindering the progress of continuous distribution, the Vice Chair advocated for completing the continuous distribution project before completely revising the LAS. One Workgroup member encouraged the Workgroup to revisit the components of Waitlist mortality and how it is currently configured in the LAS score. In terms of the processes moving forward with adding data elements, the project would require public comment and OMB approval in Spring 2020 (all OPTN data needs to be approved by OMB). Staff highly encouraged this timeline because there has been a lot of public comment feedback surrounding updating the LAS. In terms of decision making principles to determine new data elements, the Workgroup has encouraged members to base their input on literature and be evidence-based. This data could be broad, or it may be more focused on a particular diagnosis group. One member was concerned that the timeline for releasing this project for public comment next year may interfere with the continuous distribution project. Staff agreed, and will create a timeline for both projects within the next week.

Next steps:

Workgroup members will continue to provide feedback on which data elements to include for Spring 2020 public comment.

2. Fall 2019 Public Comment: Update

UNOS staff provided a brief update on the support and sentiment for the continuous distribution project across both regional and committee meetings. In general, there has been broad support for the concept paper.

Summary of discussion:

One member asked whether the Workgroup has internally discussed multi-organ allocation. There was concern from a few members that a heart/lung candidate may pull lungs from a high LAS candidate. One Workgroup member commented that years ago the Lung Subcommittee had debated whether the heart should always pull the lungs during allocation. Other members agreed that this needs to be addressed (perhaps by a LAS threshold). Staff explained that once all organs are switched to continuous distribution, this should make multi-organ allocation easier. However, for now this discussion will need to be addressed at a later date.

Upcoming Meetings

- October 10
- October 17th (in person)

Attendance

- **Workgroup Members**
 - First Name Last Name
 - First Name Last Name
- **HRSA Representatives**
 - First Name Last Name
- **SRTR Staff**
 - First Name Last Name
- **UNOS Staff**
 - First Name Last Name
- **Other Attendees**
 - First Name Last Name