

OPTN Continuous Distribution of Lungs Workgroup

Meeting Minutes

September 12, 2019

Conference Call

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Introduction

The Continuous Distribution of Lungs Workgroup met via Citrix GoTo teleconference on 09/12/2019 to discuss the following agenda items:

1. Public Comment Update
2. Discussion of Lung Allocation Score (LAS)

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

1. Public Comment Update

UNOS staff gave an update on the public comment feedback received to date for the lung continuous distribution concept paper.

Summary of discussion:

Currently, regional meeting support for the concept paper exceeds 75%. In terms of other OPTN Committees, the majority of Committees either support or strongly support the concept paper. Other key takeaways include: comments regarding a mixture of both concern for too much attention on efficiency and too little attention on efficiency; questions regarding the weighing of factors; desire to address disadvantaged groups; comments addressing potential LAS updates; and questions about multi-organ allocation. Overall, the sentiment from OPTN members and Committees has been supportive.

A workgroup member questioned the reason why the Liver Committee would oppose the concept paper. Another member clarified that there was an individual on the Liver Committee who opposes continuous distribution generally, not necessarily the concept paper itself.

2. Discussion of Lung Allocation Score (LAS)

UNOS staff began the discussion regarding updating the LAS cohort and coefficients, identifying and adding new data elements for use in future allocation analysis, and rebalancing the LAS as part of a larger effort to balance all factors.

Summary of discussion:

One Workgroup member stated that initially, the intent of the LAS was to undergo regular updates. However, there may have been unintended challenges to updating this regularly. UNOS staff recommended separating the coefficients from the actual policy language so any revisions to the LAS do not require public comment. Other members agreed, and stated that initially the coefficients were not in the policy language. SRTR asked for clarification whether this would require a data request. UNOS staff agreed to look further into how best to initiate the process under the new contract.

SRTR commented that coefficients for PSRs are updated every 6 months, with model rebuilding every three years. However, though this might increase workload and burden, SRTR staff agreed that the LAS coefficients should be updated more frequently. This frequency would be dependent on how much the relationship between cohorts (predictive factors) change in relation to outcomes over time. For example, you could update the coefficients using a new cohort, but find that the overall results (for instance, waiting list mortality or post-transplant outcomes) did not change much. Another example was how a journal articles co-authored by some SRTR staff found that FEV1 for cystic fibrosis patients became a more significant predictor of mortality after the researchers had updated the cohort on their own.

In terms of other organs, SRTR commented that they update the mapping table from KDPI to KDRI and compare the distribution. This happens annually, and the Kidney Committee reviews the results, but cannot recommend changes. UNOS staff clarified that updating the coefficients on a more regular and routine basis will actually decrease the potential for human error. The SRTR member agreed, and acknowledged that there are currently no errors with updating the KDPI. In terms of PSRs, these reports are updated automatically and do not include much chance for human error.

There was concern from some members that updating the LAS could result in less resources being devoted to other projects, such as continuous distribution. However, if updating cohorts and coefficients prior to updating the LAS occurred, this may not require as many resources. Also, adjusting cohorts would allow the Workgroup to see how patient diagnosis groups are changing (such as pulmonary hypertension or COPD).

SRTR voiced concern about having the TSAM updated prior to January 2020 public comment, and stated that it may not be needed. The SRTR suggested comparing the old LAS to the new LAS, which may still provide substantial information (except for predictive analysis). An example would be looking at the change in LAS for diagnosis groups over time. One Workgroup member was concerned that refitting the LAS model would need TSAM modeling, especially if data variables would be added or removed. This process of removing and adding data variables would require public comment. UNOS staff clarified that the Workgroup would not be requesting new variables to be added or removed during Spring 2020, only to update the LAS more frequently. The current LAS cohort uses data from 2006-2008. SRTR stated that in order to provide an update to the LAS, this would only require data analysis comprising of newer patients (more recent cohort), newer coefficients and would not change the variables. SRTR stated that they believed this could be done prior to late November, and ready for Spring 2020 public comment. In terms of updating the LAS cohort, SRTR members stated that if there other variables (outside of demographics) then they would need to know this prior to updating the cohort and creating new coefficients for public comment. In terms of socioeconomic status, SRTR commented that these may not be variables available nor collected, such as median income or zip code. They acknowledged that this is a frustration for many members. In terms of candidate registration, SRTR commented that though they collect 5-digit zip codes, this is a poor indicative for socioeconomic status. However, a member was concerned about which data could be collected on vulnerable populations, and UNOS staff commented that the Minority Affairs Committee is already looking at this.

In the end, Workgroup members were supportive of having the LAS cohort and coefficients updated and standardized on a more regular schedule. Also, members agreed that they need to ensure that they do not update the cohorts or coefficients too frequently or too infrequently.

Next, Workgroup members began discussing which new data elements to use in future allocation analysis. Leadership clarified that these data elements would not be added to the LAS, only that the Workgroup would start to collect the data for future use. One member stated that height, weight, and blood type are important factors that should be considered for data collection and factored into the LAS.

Another member noted that some of these variables are already being collected, and could be more easily incorporated. Leadership clarified that these are factors that have already been considered by the lung continuous distribution workgroup, specifically for the composite score. There was concern about completely re-doing the LAS due to amount of time it would take, and that some of these factors could be incorporated into the continuous distribution system rather than overhauling the LAS. Other members agreed that these factors should be included in both the continuous distribution system and the LAS. There was concern from an SRTR member about weighing factors that are not currently being collected, and included on an ad hoc basis for continuous distribution. However, UNOS staff clarified that the purpose of the discussion is to determine data elements that need to be collected right now, for further analysis and incorporation into the LAS later on. Another Workgroup member suggested that members submit evidence and data-driven suggestions for data elements to be added. Also, this member suggested focusing on particular diagnosis groups, and supporting their opinions with literature.

Next steps:

UNOS staff will provide more information regarding how frequently other organs systems, such as kidney, are updating their scores (e.g. KDPI). UNOS staff will craft a data request for SRTR to update the LAS cohorts and coefficients for Spring 2020 public comment. UNOS staff will also collect input from Workgroup members regarding additional data elements they would want to begin collecting for the LAS score.

Upcoming Meetings

- October 10, 2019
- October 17, 2019 – In-person Committee meeting
- November 14, 2019
- November 21, 2019