Introduction

The Full Thoracic Committee met via Citrix GoTo teleconference on 07/18/2019 to discuss the following agenda items:

1. Continuous Distribution of Lungs: Review Concept Paper
2. Regional Meeting Update

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

1. Continuous Distribution of Lungs: Review Concept Paper

UNOS staff gave a high level presentation of the continuous distribution of lungs concept paper. The objective of this presentation was to prepare non-lung workgroup members for regional meetings, and to receive feedback on the presentation.

Summary of discussion:

During the presentation, Committee members generally thought the paper was clearer and easier to comprehend. However, there were questions raised regarding the four attributes used in the examples: ischemic time, travel mode, blood type, and medical priority. A few Committee members were concerned that these were the only four attributes that would be included in the lung continuous distribution model and whether the thoracic community had been consulted prior to the writing of this concept paper. UNOS staff clarified that the attributes used in the examples are the attributes found in current lung policy. Also, the Continuous Distribution of Lungs Workgroup had discussed other attributes to add in the future, but they had decided to start smoothing the boundaries of the current attributes before adding more attributes. Committee members thought that there might be overlap between travel mode and ischemic time, because they are “inter-related” (except for perhaps EVLP). Another Committee member stated that it would be helpful to include in the paper and presentation all the attributes the Workgroup had considered, and to make clear that the four attributes listed are only a sub-set used as examples. It would also be helpful to include how the statistical modeling for the continuous distribution system was developed, because there are many ways in which statistical models can be “influenced”. Other Committee members asked whether each organ system would have their own attributes. An example from one Committee member was that certain attributes would impact other organs more than others, such as donor size being more impactful for hearts than for kidneys. UNOS staff confirmed each organ system would have its own attributes, and that some attributes across all organs had already been identified and linked to components of the Final Rule. To make this clearer in the paper, UNOS staff will include a graphic focusing on lung and its specific attributes. UNOS staff also clarified that the purpose of the regional meetings was to both educate the public about the concept, and to receive their feedback.

Next in the discussion, one Committee member commented that a general layperson would not understand the following sentence as it appears in the Proposal at a Glance: “are there other hard
boundaries in organ allocation that could be smoothed through the use of point-based allocation”. This member stated that the term “smoothed” should be rephrased under the “proposal at a glance” section. Furthermore, there was concern that the outcomes score section in the paper was difficult to understand because there were unfamiliar acronyms used (e.g. EPTS, ABDR) and that it was vague. Also, though UNOS staff was praised for describing the ethicality of the concepts, a few members thought that the paper had expanded beyond its scope of focusing solely on geography. One Committee member suggested that the paper specifically states that this concept is meant to optimize the organ allocation system.

Another point of difficulty in the paper was the weighing of attributes against each other. For example, within the LAS score, you could determine how meaningful it would be to fly versus drive, but that this may prove to be more difficult when comparing against ischemic time or sensitization. A suggestion was that certain candidates could be given boost points to increase their composite score. This began the discussion into how the continuous distribution system would be measured, and one Committee member opined that the Committee should decide this now prior to public comment. One suggestion for measuring the new allocation system was to look at survival pre versus post-implementation. UNOS staff agreed that there are various ways in which to measure the new allocation system, with survival rates being only one metric.

Discussion continued into speaking about the current heart allocation, and the lack of a continuous scoring system for this organ system. There was criticism that heart allocation does not have reliable predictive models for post-transplant outcomes, because real-life patients usually do not match what the SRTR models. Also, there are no measurements on quality of life for heart allocation, which could impact how a continuous distribution system is measured. One Committee member stated that though a new heart allocation system would be dependent upon the 1-year data report, this report may not accurately reflect the changing of a practice’s behavior or listing criteria. UNOS staff responded that the Committee may not necessarily have to develop an outcomes or net benefit score immediately. However, it may be argued that each organ system does include outcomes in their allocation systems by using geography (e.g. ischemic time). The question might be how we weigh geography against wait-list time, which heart already does in their allocation system. Since more post-policy implementation data will be needed prior to heart changing their allocation system, it was decided that the lung system should adopt continuous distribution first.

One Committee member asked whether the Workgroup intended to separate the components of the LAS score, because both for medical urgency and transplant benefit, the variable “waitlist mortality” is counted twice. This member argued that if the Workgroup decided to adjust the LAS score in order to weigh the second medical urgency variable differently than the first medical urgency variable, then this may optimize the LAS score. However, the intention or lack of intention to adjust the LAS should be made clear at regional meetings. UNOS staff agreed that the LAS score could be broken out now, but that it did not need to be. Such a discussion would need to be decided by the Workgroup, and Committee leadership will be consulted.

In continuing the discussion, UNOS staff spoke to the weighing of attributes, and how this process will be consensus driven and accomplished via modeling. UNOS staff plan on employing a technique called “multi-decision criteria making”, whereby multiple goals will be maximized and prioritized (e.g. waitlist mortality versus post-transplant outcomes). The plan is to first re-construct the current policies into a new composite score system. Then, UNOS staff will work through a gap analysis between the new composite score system and an idealized version of the system. However, the majority of this process was not discussed in the paper, because staff intended for the community to understand the overall
concept prior to delving into the details. One Committee member stated that though they understood the reasoning for omitting these details, they believed that UNOS staff need to be sure that the process for using these methodologies is transparent and is understandable by the community. This member encouraged a separate meeting be convened to determine how best to present the methodology information to the public. Another general sentiment felt by some members was that it would take a long time for UNOS staff to build trust with the community because it may be difficult to ask clinicians to accept a new allocation system based on algorithms computed via technology. This

Next steps:

UNOS staff will revise the continuous distribution paper and regional meeting presentation based on the feedback from the Committee today.

2. Regional Meeting Update

UNOS staff presented a brief update on the regional meetings and scheduled presenters. The presenters will make two presentations: one at the main meeting and another during the thoracic breakout sessions. UNOS staff is in the process of setting up regional prep-meetings for the scheduled presenters.

Upcoming Meeting

- August 2- October 2: Public Comment