

**OPTN Thoracic Lung Workgroup
Meeting Minutes
June 20, 2019
Conference Call**

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Introduction

The Lung Workgroup met via Citrix GoTo teleconference on 06/20/2019 to discuss the following agenda items:

1. Continuous Distribution of Lungs: Concept Paper and Methodology Overview

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

1. Continuous Distribution of Lungs: Concept Paper and Methodology Overview

UNOS staff provided a high-level overview of the concept paper and the methodologies discussed in the paper. Workgroup members provided input and feedback regarding the structuring and content of the concept paper.

Summary of discussion:

UNOS staff asked the Workgroup members whether the concept paper made sense, was understandable, contained too strong of statements or conclusions, and what information the Workgroup wanted to obtain from the public. In response, one Workgroup member expressed a desire to solicit feedback from other organ-specific members (besides lungs) because this would allow people to weigh in on these issues prior to implementation. This Workgroup member suggested that a broader concept paper based on the continuous distribution framework be developed for a larger audience, and another concept paper developed for how the new framework will specifically work with lung policy. There might be separate presentations at regional meetings as well, because separating the information might increase participation from a larger audience. Another Workgroup member was concerned that there was not enough background information, especially for those members not aware of the work done by the Ad Hoc Geography Committee. Other Workgroup members asked how the new continuous distribution system will be compared to other prior allocation systems, with the suggestion to include more policy background (e.g. why this geographical framework was chosen). Another suggestion was to de-emphasize geography in the concept paper, and elaborate more on other factors such as ischemic time and how they contribute to the composite score.

There was concern from one Workgroup member that this project will not de-construct the LAS score, and that the priority score should be based appropriately on medical priority. Another suggestion was to expand on how the system could improve the allocation of lungs via taking into consideration donor availability or population density so that candidate's near an airport are not over-prioritized. Other Workgroup members agreed and stated that population density should be taken into consideration now rather than later in the project.

UNOS staff shared the potential public comment questions with the Workgroup. The questions were:

- At what length of time does your institution change the mode of distribution for lungs from driving to flying?

- Should the Workgroup: a) maintain categories of ages; b) pursue a scale for age; or c) pursue a scale for size matching?
- Considering this construct, what should the OPTN consider as to how this will be used in other organ systems?

In terms of public comment questions, a Workgroup member asked whether a question about waiting time should be asked during the public comment cycle. There have been discussions about whether to use waiting time as a tie breaker or if it should be included as an attribute. Another Workgroup member suggested factoring waiting time into the distribution system above a certain LAS threshold, and can act as a trigger for moving candidate up the list (for example, heart-lung candidates may benefit from this).

Other suggestions for public comment included the following:

- Are children being treated fairly using age as the primary scale factor in the policy?
- Are small adults disproportionately affected because they are not classified as children?

In terms of pediatrics, Workgroup members generally supported using points that might be used for size and age matching in the medical priority score. One Workgroup member did express hesitance at discarding the policy that allows pediatric patients under 12 years old priority access to pediatric lungs. Due to the robust discussion, UNOS staff will make the age section of the concept paper less directional and prescriptive for now.

Another Workgroup member stated that the third public comment question was too confusing due to a lack of context (“considering this construct, what should the OPTN consider as to how this will be in other organ systems?”). For the first question, there was concern that this question was too focused on cost, whereas it should focus on efficiency (“at what length of time does your institution change the mode of distribution for lungs from driving to flying?”). UNOS staff clarified that the reason for looking at travel mode is to derive cost information. However, there was concern that this would not encompass the whole issue, because there are centers that would need to fly all the time based on where they are located. Instead, the Workgroup suggested looking at what threshold does flying become meaningful. SRTR staff commented this will be difficult to get approval from the community, because it may be perceived badly if a transplant center were not to spend an extra amount of money to procure an organ for a very sick candidate. Furthermore, SRTR staff said that this might not be defensible, and that the paper should not discuss cost, but rather efficiency or outcomes (e.g. ischemic time). However, a few Workgroup members stated that financial costs are an important factor for transplant programs, and it; therefore, is a valid issue. Workgroup members agreed that cost may be valid for programs, but that for candidates the cost is not important, and that resource allocation or utilization risk should be prioritized.

Another Workgroup member opined that they should ask the community if there are other ways in which this continuous distribution system might function that makes the current lung allocation system better.

Last, there were general concerns from Workgroup members that the methodologies in the concept paper are dense and difficult to understand. Due to this, the Workgroup thought it might be helpful to include more information about how decisions will be made during this process (e.g. reducing bias or subjectivity).

Upcoming Meeting

- July 11