

**OPTN Thoracic Committee: Continuous Distribution of Lungs Workgroup
Meeting Minutes
June 13, 2019
Conference Call**

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Introduction

The Continuous Distribution Workgroup met via Citrix GoTo teleconference on 06/13/2019 to discuss the following agenda items:

1. Continuous Distribution of Lungs: Methodology Overview
2. Announcements

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

1. Continuous Distribution of Lungs: Methodology Overview

UNOS staff presented and discussed possible methodological approaches that may be incorporated into the continuous distribution framework.

Summary of discussion:

UNOS staff recommended that the Workgroup finish building a rating scale for each attribute; replicate current policies using new methodologies; collect feedback from the Workgroup on priorities; and refine weightings with the Workgroup. In response, most of the Workgroup thought that the literature papers about methodologies were dense and difficult to understand. One Workgroup member encouraged UNOS staff to acquire feedback from the community about the methodologies under evaluation. It may also be especially important to get the necessary feedback from the community in case there is something which the Workgroup might not have thought of. This member also encouraged selecting methods that are transparent so that people understand how any conclusions were made, especially if the frameworks will be used for other organ allocation systems. A suggestion was made to consult with the Institute for Operations Research and the Management of Sciences (INFORMS) when reaching out to the transplant community. UNOS staff stated that they have reached out to the different authors of the literature papers, and that the methodologies are already well-established. Furthermore, UNOS executive leadership have spoken about hiring consultants to train UNOS staff in the methodologies for when other organ systems must go through a similar process. In addition, there is an outreach plan in place for regional meetings and getting feedback from community.

Other concerns from Workgroup members included whether the methodologies were being used operationally in the U.S., in what industries the methodologies were being used in, and whether they have been used in healthcare. UNOS staff clarified that to their knowledge the methodologies are probably not being used in the U.S., though they have been used internationally for project management and prioritization (e.g. environmental projects). However, there are healthcare methodology examples, and UNOS staff will follow-up with an email containing these examples. Workgroup members felt that healthcare examples would be helpful for understanding the methodology processes and understanding how outputs are derived.

One Workgroup member expressed a concern for how the "preference decision-making" group would be decided for this project and impact the processes with their biases. This Workgroup member opined

that the decision-making processes need to be consensus-driven and transparent so that the transplant community will support the outputs and be unbiased. UNOS staff responded that there is literature available describing how to best to compose and form a decision-making group (such as choosing who to be involved) and how to build consensus. Right now, this project will probably solicit feedback from a broader group, but that the Committee will be the one to make the final decision.

This same Workgroup member commented that it appears the construct is linear, in that each of the factors has a weight that is additive, not relational. For example, a candidate with a medical urgency LAS score of 35 might not have the same geographic priority as a candidate with a LAS of 80. In this way, a candidate with a LAS of 80 should have organ priority over a candidate with a LAS of 75, but maybe not necessarily a candidate with an LAS of 40 versus a candidate with an LAS of 35 (e.g. the sicker you are the more weight should be given to distance). UNOS staff have discussed this, and clarified that the factors are additive but not linear; within each factor there is non-linearity. This issue can be addressed further by having different boundaries based on medical urgency and the slope may change.

The Workgroup member continued the discussion by asking about the relationship between distance and population density. For example, if you are 500 miles away starting in Kansas versus New York, then there are significant differences in number of candidates. UNOS staff acknowledged that this is true, but that this is a different factor not currently in the system, but which may be incorporated later. A possible solution may be to add boost points to certain populations in order to equalize access.

An SRTR staff member stated that it might be worth thinking about the competing interest and goals for organ allocation. This member opined that we should place minimum weight on geography and do the most sharing feasible. This SRTR member stated that the community should not be asked about the relative weight of geography. However, other Workgroup members disagreed and stated that dialogue should not be pushed away from the community as distance has a huge financial impact on programs. UNOS staff also stated that each factor needs to be weighted, but can be phrased to the community carefully and explicitly.

Another Workgroup member commented that there needs to be large group of stakeholders involved in order to gather enough sentiment to adjust the weights accordingly. Also, a larger group is needed to reduce bias. UNOS staff stated that researchers have agreed, and that is why staff want to use match-run data. Furthermore, UNOS is planning on getting feedback from the whole community while tracking demographic information in order to ensure that bias and individual preferences are reduced. UNOS will continue to work with other researchers to decrease bias within this policy's development process.

Next steps:

UNOS staff will follow-up with literature papers highlighting healthcare methodology examples.

2. Announcements

The data request was submitted to HRSA today on June 13th. Also, UNOS staff will be sending the Workgroup a draft concept paper for feedback. UNOS staff asked that the Workgroup provide them with any specific questions to ask during public comment. UNOS staff also asked for the Workgroup members to inform their colleagues about the concept paper and to encourage them to review and comment during the fall 2019 public comment cycle.

Upcoming Meeting

- June 20, 2019