

**OPTN Minority Affairs Committee
Meeting Minutes
May 20, 2019
Conference Call**

**Sylvia Rosas, MD, MSCE, Chair
Irene Kim, MD, Vice Chair**

Introduction

The Minority Affairs Committee (the Committee) met via Citrix GoToTraining teleconference on 05/20/2019 to discuss the following agenda items:

1. Monitoring of the Lung Allocation Change, 1 Year Report
2. Prioritizing Project Ideas from In-Person Meeting

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

1. Monitoring of the Lung Allocation Change, 1 Year Report

The Committee reviewed the one-year data report on the policy change to remove DSA from lung allocation.

Data summary:

Monitoring began upon implementation of the emergency action lung policy change on November 24, 2017. The primary goal of the policy was to address concerns over compliance with the Final Rule. Based on the first 1 year of data collection post policy:

- An expected change was seen in the distribution of match Lung Allocation Score (LAS) at transplant for recipients. As predicted there was an increase in the mean match LAS at transplant. This change and its magnitude varied across OPTN region.
- An increase was seen in the median distance between donor hospital and transplant center and a decrease in the number of local lung transplants. However, the majority of lungs are allocated within the first unit of allocation (250 nautical mile radius from the donor hospital).
- There was an increase in the death rate overall, but some LAS groups saw a decrease in the death rate.
- There was a decrease in the transplant rate overall, but some LAS groups and diagnosis groups saw an increase in the transplant rate.
- There was a decrease in deceased donor utilization nationally, but the impact varied by OPTN region.
- The national discard rate increased, but varied by OPTN region.
- Nationally, there was an increase in ischemic time and time from first electronic offer to cross clamp.
- The number of additions to the lung waiting list increased. However, the cohort does not show evidence of change with respect to diagnosis group.
- Nationally, there was an increase in the number of lung alone transplants, but this varied by OPTN region.
- Nationally, there was an increase in the number of donation after circulatory death (DCD) donors.
- The recipient cohorts do not show evidence of a difference across eras with respect to diagnosis group, procedure type, donor type, or ABO.

Summary of discussion:

The Committee had several questions in regards to the data presented. On the slide that showed the scatter plot of center volumes in the pre policy change era compared to the post policy change era, the Committee chair asked if there are any similarities in the centers that experienced a lower volume of transplants in the post era compared to their pre era volume. UNOS staff answered that at this time, it is unclear if there are any similarities between those centers. As time goes on and more data become available, then trends may emerge.

The Committee expressed concern over the increased discard rate in the post era compared to the pre era. The question was asked if there are any specific factors that played into the increased discard rate? UNOS staff answered that there are many factors that play into discard rate other than the policy change. For example, lung perfusion has seen an increase over the past year, which may also play into the increase in discard rate. More marginal lungs, that historically would not have been pursued, have been procured because of lung perfusion but they are not always utilized.

One Committee member stated that the data in the report show a positive outcome for broader distribution. With broader distribution on the horizon for the other organs, the lung data can be used as an argument in support of the coming changes.

Another Committee member made the argument that it is possible that the policy change was actually detrimental to the utilization rate for lungs. The utilization rate remained relatively the same between the pre policy change era compared to the post era. During that time period, there was also an increase in organ donors. Had the number of organ donors remained the same throughout both periods then there could have been a lower rate of lung utilization. UNOS staff commented that it is hard to make an assumption of that nature since there are many factors that play into utilization rate.

Lastly, one Committee member asked if there was any data on the distance traveled for accepted lungs and the organ acquisition fees associated with traveling for lungs. UNOS staff replied that data was not collected on organ acquisition fees, but that in terms of distance traveled over seventy-five percent of lungs traveled less than 250 nautical miles in the post policy change era.

2. Prioritizing Project Ideas from In-Person Meeting

Each Committee member was asked to rank their top three project ideas from the list of project ideas that was compiled during their March 2019 in-person meeting held in Richmond, VA. The ranking was to drive discussions to help the Committee select their next project.

Summary of discussion:

Due to the fact that only half of the Committee members submitted their top three project rankings, those on the call felt that they would not be able to select a project for the Committee to focus on next until everyone submitted their rankings. The Committee chair suggested that the remaining time be spent discussing the ideas, but not selecting a project to work on next.

One Committee member commented that the project idea on analyzing post-geography allocation changes seems too premature of a project. Most of those changes have either not gone into effect or have only been in effect for a very short period. A UNOS staff member asked Committee members to further clarify what they wanted in a project focused on analyzing discard rates and decline code usage. A Committee member clarified that the current list of decline codes available on DonorNet are vague and do not give a good picture of why an offer was refused. A UNOS staff member said that there is an internal project looking at the current list of decline codes and that it is not part of an OPTN committee project.

Another Committee member brought up the project idea focusing on MELD score as an indicator of sickness and suggesting that in addition to looking at potential racial/ethnic disparities in terms of MELD score to also looking into potential disparities for elderly patients and those that live in areas of the country where access to medical care is more difficult. Another member suggested that the project also focus on the mortality rates at specific MELD scores to see if there is a specific liver disease associated with the mortality rate.

Lastly, a Committee member brought up the project idea about patients with intellectual disabilities and access to transplant. He is aware that the OPTN Ethics Committee's project on the same topic is currently on hold, but feels that the Committee could do their own analysis asking those centers who perform a high volume of transplants for patients with intellectual disabilities what are their best practices. A UNOS staff member commented that any work on such a project would need to wait until the Office of Civil Rights under Health and Human Services release their ruling on using intellectual disabilities as a listing criteria for transplant.

Next steps:

The Committee chair asked that any Committee member that had not submitted their top three project ideas to send that to UNOS staff as soon as possible. The Committee can further discuss and select their next project on the next full Committee call in July.

Upcoming Meetings

- July 15, 2019 (teleconference)
- September 16, 2019 (teleconference)
- September 23, 2019 (Chicago, IL)