

## **OPTN Minority Affairs Committee**

### **Meeting Minutes**

**September 23, 2019**

**In-Person Meeting**

**Irene Kim, MD, Chair**

**Paulo Martins, MD, PhD, Vice Chair**

### **Introduction**

The OPTN Minority Affairs Committee (MAC) met in Chicago on 09/23/2019 to discuss the following agenda items:

1. Welcome and Introduction
2. Review of MAC Charter
3. OPTN Kidney Transplantation Committee, *Eliminate the Use of DSA and Region from Kidney Allocation Policy.*
4. OPTN Pancreas Transplantation Committee, *Eliminate the Use of DSA and Region from Pancreas Allocation Policy.*
5. OPTN Thoracic Transplantation Committee, *Continuous Distribution of Lungs*
6. Socio-economic Status (SES) Project
7. OPTN Policy Oversight Committee (POC) Update
8. Project Ideas Discussion
9. Closing Remarks and Adjournment

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

#### **1. Welcome and Introduction**

The MAC began their in-person meeting by discussing an article titled "[Disparities in Acceptance of Deceased Donor Kidneys Between the United States and France and Estimated Effects of Increased US Acceptance](#)".

##### Summary of discussion:

Members reported that they believe organ utilization could be increased in the United States. A member commented that the utilization rate in France could be higher due to major differences, including France's public healthcare system where everyone is a stakeholder. Another member reported that hospitals in the United States are more focused on outcomes and therefore less likely to accept a risky organ.

##### Next steps:

After this opening discussion, MAC turned their attention to their committee charter.

#### **2. Review of MAC Charter**

The MAC reviewed their committee charter.

##### Summary of discussion:

The committee voted to change 'underserved populations' to 'vulnerable populations'. The charter now reads:

“The Minority Affairs Committee identifies and considers aspects of organ procurement, allocation, and transplantation with the potential to impact minority or ~~underserved~~ vulnerable populations in particular. In addition, the committee provides input and recommendations regarding ongoing efforts of other OPTN Committees and the Board of Directors to ensure that issues and special needs of minority or ~~underserved~~ vulnerable populations are considered and addressed.”

Next steps:

UNOS Staff will submit this charter change to the OPTN.

### **3. OPTN Kidney Transplantation Committee, Eliminate the Use of DSA and Region from Kidney Allocation Policy.**

A representative from the Kidney Transplantation Committee presented their proposal and sought feedback from MAC.

Summary of discussion:

Overall, the committee supports the direction of the proposal, but some members wanted the OPTN Kidney Transplantation Committee to consider a smaller circle size than the proposed 500 NM circle. Please note that some MAC members were in favor of the 500 NM radius. A member raised the concern that smaller cities have limited access to direct flights, thus potentially increasing cold ischemic time during transportation. A smaller circle size would allow for more driving of kidneys, keeping cold ischemic times lower.

It was also mentioned that the Kidney committee should consider adding a safety net provision for multi-organ candidates, specifically for thoracic/kidney allocation (to model after the current liver/kidney provision already in place) to discourage unnecessary kidney listing. Lastly, a committee member raised the concern about Alaskan donors. Since there are no transplant centers in Alaska, all kidneys from Alaska would go straight to national allocation, and that could potentially be an inefficient allocation scheme. The committee supports the proposal but would like the Kidney committee to consider adding language to the proposal that would consider any kidney donor in Alaska as originating from the Seattle-Tacoma International Airport (Sea-Tac) in Seattle, Washington.

**Vote-**

Kidney Allocation proposal: **4 Strongly Support, 4 Support, 1 Neutral/Abstain, 0 Oppose, 1 Strongly Oppose**

Kidney Allocation Proposal with Sea-Tac variation: **4 Strongly Support, 5 Support, 1 Neutral/Abstain, 0 Oppose, 0 Strongly Oppose**

Next steps:

The MAC’s commentary and sentiment will contribute to the development of this policy.

### **4. OPTN Pancreas Transplantation Committee, Eliminate the Use of DSA and Region from Pancreas Allocation Policy.**

A representative from the Pancreas Transplantation Committee presented their proposal and sought feedback from MAC.

Summary of discussion:

A Committee member suggested that some programs may not accept a pancreas procured by another program. The presenter noted that the use of proximity points will help decrease travel and limit the necessity of having other surgeons procure the pancreas. The Committee discussed whether patients

would still benefit from multi-listing, since broader distribution should improve equity in access to transplant. However, it was also noted that programs may vary in listing practices and offer acceptance, so multi-listing may still benefit the patient. The Committee discussed how vulnerable populations may not be able to travel and multi-list, which could impact their access to transplant. The Committee asks the Pancreas Committee to consider this potential inequity in access to transplant when evaluating the proposed impact of removing DSA and region.

The Committee expressed concern about non-contiguous areas such as Hawaii, Puerto Rico, and Alaska, where 500 NM circles around donor hospitals would cover water or areas without any programs. A Committee member explained that pancreata are imported and transplanted from Alaska, despite the distance, and suggested that the same variance that exists for liver should be applied to both kidney and pancreas (treating organs from Alaska as from Seattle-Tacoma International Airport). Committee members suggested that the Pancreas Committee could look into whether and how often pancreata are imported from Hawaii, to identify if a disparity exists for Hawaii exporting more pancreata than it imports for its patient population. Overall, the Committee supported a modified proposal that included a variance for Alaska.

Vote- Pancreas Allocation proposal: **3 Strongly Support, 6 Support, 1 Neutral/Abstain, 0 Oppose, 1 Strongly Oppose**

Next steps:

The MAC's commentary and sentiment will contribute to the development of this policy.

**5. OPTN Thoracic Transplantation Committee, Continuous Distribution of Lungs**

A UNOS staff member presented their proposal to elicit feedback from MAC.

Summary of discussion:

Members commented that determining a weighted system for each organ will be difficult, but that severity of a patient's disease should be considered important. Members asked how candidate age group would play out in the continuous distribution of lungs. Committee members questioned what weight should be given to Cold Ischemic Time when compared to medical priority.

Vote- Continuous distribution of Lungs: **2 Strongly Support, 6 Support, 1 Neutral/Abstain, 0 Oppose, 1 Strongly Oppose**

Next steps:

The MAC's commentary and sentiment will contribute to the development of this policy.

**6. Socio- economic Status (SES) Project**

The MAC was given an update on the status of the SES project. The SES project will shift from a workgroup project to a full committee project. Committee members discussed which data fields would be most appropriate to request.

Data Summary:

Currently collected by the OPTN:

- State and ZIP code of residence
- Ethnicity/Race
- Citizenship
- Highest level of education

- Working for income
- Primary source of payment
- Date of birth

Summary of discussion:

During past SES project meetings, the workgroup proposed the following data elements:

- Household income & Size
- Individual Income
- Expanded “Working for Income” Options like LDR
- Access to Transportation
- Veteran Status
- Gender

A MAC member reported that the data currently collected by the OPTN is not granular enough to investigate the impact SES has on allocation inequity and transplant outcomes. This member acknowledged that the data burden is high, but noted that the selected element will be essential in the collection of information surrounding SES and its relation to access/equity in transplant.

The MAC discussed the data that is already collected by the Centers for Medicare and Medicaid (CMS), including data on renal dialysis. It was noted that minimal SES data was collected and that these forms are not always completed in a detailed or accurate way. A member suggested that the new executive order could be used to support an argument for more data collection.

The MAC discussed each proposed element and assessed which would be the most important to request in the proposal. Their goal was to narrow the choices and come closer to making a final decision on a field. The committee quickly eliminated access to transportation because members determined that its meaning was vague and could be interpreted many different ways.

Committee members thought that household income and size were useful data elements to consider. When collected together, these data can measure household poverty. The Federal Poverty Level (FPL) is a measure used and understood across the country. Veteran status was also discussed, but one member thought the field should be revised to “eligibility for coverage by the VA”. After more discussion, veteran status, along with individual income, expanded “working for income”, and gender were eliminated because members felt that when collected together, household income and size were the best indicators of SES. It was explained that the collection of this data straight from patients would be more granular and accurate than the use of zip code data. The members also learned that the fields would have to be entered as in a text box as one number(as opposed to a range) in order to be useful when calculating a household’s level of poverty.

Next steps:

The MAC will seek input from the OPTN Transplant Administrators Committee (TAC) and the OPTN Transplant Coordinators Committee (TCC) on their chosen fields at the October and November monthly committee meetings.

**7. OPTN Policy Oversight Committee (POC) Update**

POC’s new policy priorities and structure was presented to MAC.

Summary of discussion:

Under the new OPTN contract with HRSA the POC is functioning as an OPTN operating committee. In this new structure, the strategic plan will be more connected to committee projects and utilize themes. The POC has three current areas of focus:

1. Continuous Distribution
2. More efficient donor recipient matching to increase utilization
3. Improved equity for multi and single organ candidates.

Next steps:

Understanding the POC's new structure, the MAC moved on to a project brainstorm session.

**8. Project Ideas Discussion**

A list of project ideas was presented to MAC. Members were asked to give feedback on these ideas and indicate any interest.

Summary of discussion:

The MAC discussed the presented projects. They showed interest in:

- "Analysis of post- geographic allocation data for lung, liver and kidney, six and one year data."
- "Analysis of discard rates, decline codes and one- year graft outcomes."
- "Analysis of MELD as an indicator of sickness, Is MELD a good indicator of sickness for all racial/ethnic populations or are certain groups not accurately represented by MELD?"
- "Analysis of the racial makeup of the kidney waiting list. Are minorities proportionally disadvantaged, potentially by Multi- Organ Transplant (MOT)?"

The MAC also requested an update from the Living Donor Committee on their Social Media project.

Next steps:

UNOS staff will send each MAC member a poll that asks them to indicate which of these projects they are most interested in moving forward with. The MAC meeting then concluded.

**Upcoming Meeting(s)**

- October 21, 2019 (Teleconference)
- November 18, 2019 (teleconference)