

**OPTN/UNOS Minority Affairs Committee
Meeting Minutes
September 17, 2018
Conference Call**

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Introduction

The Minority Affairs Committee (MAC) met in-person and via teleconference on 09/17/2018 to discuss the following agenda items:

1. MAC News
2. Potential Disparity in Non-Contiguous Access
3. Socio-Economic Status and Access to Transplant
4. Review of Geography Frameworks
5. Spring Public Comment - MAC Engagement
6. MAC Checklist

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

1. MAC News

The Committee discussed news relevant to the MAC. A paper was published on waitlisted racial disparities declining post KAS that has some recommended improvements. A paper was published on KAS A2/A2B policy on access to transplantation among minorities compared to whites. A third paper was published on exploring lifting barriers to living organ donation. There are three studies (Beth Israel, University of Pennsylvania, and a national study) looking at living donors' lost wages to see if that makes an impact on whether one donates or not.

2. Potential Non-Contiguous Disparity in Access

The MAC reviewed a data analysis and feedback from a Subcommittee tasked with looking at whether non-contiguous US areas such as Puerto Rico and Hawaii have a disparate access to transplant compared to the continental US.

Data summary:

The data analysis looked at all liver donors between July 2013 and August 2017. The analysis showed that Hawaii has a low volume of livers recovered and Puerto Rico is in the mid-to-low range. Most of the country had more registrations than livers recovered, but there were 3 Donor Service Areas (DSAs) including Puerto Rico that had more livers recovered than registrations that were waiting. The high transplant rates indicate that access to transplant is not the issue. Death with lower model for end-stage liver disease (MELD) scores are higher in Puerto Rico, which has both a higher transplant rate and at the same time a very high waitlist mortality rate.

The analysis also reviewed exporting versus importing trends for Hawaii and Puerto Rico. More livers were exported than kept overall. Importing trends showed about 7 times more livers were exported than imported in Hawaii and about 12 times more exported than imported in Puerto Rico. Overall, their transplant rates are 3 times more than the average center in the US.

In Hawaii there is a variance where blood group B patients (hard to match and overrepresented in Hawaii) get greater access to blood group O organs before organs are exported to continental U.S. In Puerto Rico, blood type O is overrepresented with 54% being O and in the rest of the U.S. 46%. The data analysis overall shows that Hawaii and Puerto Rico export more livers than

they import, candidates in Hawaii have average or above average access to transplant, and candidates in Puerto Rico have higher waiting list mortality than other parts of the country.

The analysis also identified how liver allocation could impact access to transplant for non-contiguous areas. The proposed changes using concentric circles would not encompass the geographically isolated Hawaii, Puerto Rico and Alaska. The implication is that high MELD/status 1A candidates may receive national offers, where under the current system they receive regional offers. Similarly, candidates in regions 6 and 3 that currently receive regional offers from geographically isolated areas before offers go to the national level would only receive those offers at the national level. The changes to allocation would impact all of the liver programs differently, so it is difficult to tell what the net implication is going to be for non-contiguous areas.

There were 5 liver imports over 4 years (average of 1 per year) for Hawaii and 15 over 4 years (average of 4 per year) for Puerto Rico. The exported number of livers was 34 for Hawaii (average 8 per year) and 182 for Puerto Rico (average 45 per year). The changes to the liver allocation system would probably mean more livers staying in Hawaii and Puerto Rico because an offer would be allocated to the non-contiguous area and then to the national level without differentiating between areas of the contiguous US that are closer or farther from the non-contiguous area.

High MELD and status 1A candidates from Hawaii and Puerto Rico could be disadvantaged because they receive fewer offers outside the geographically isolated area; however, more organs may stay in Hawaii and Puerto Rico because lack of regional sharing. Also, organs recovered in non-contiguous areas accrue longer cold ischemic times (CIT) and there could be a higher discard rate if CIT increases because the offers at the national level are not differentiated based on proximity to the geographically isolated area. A limitation of the analysis is that there are few livers from non-contiguous areas, so the data set is small.

Summary of discussion:

One Committee member felt with the transplant rate as high as it is in Hawaii and Puerto Rico, they would potentially have less of a disadvantage because their rate will come down to what national rates are. Allocation-wise, there is room to allocate from non-contiguous to contiguous areas because that transplant rate could become more similar to what the national average is. However, another member expressed concern that very sick candidates in Puerto Rico are not getting the organs they need. To help the candidates in Puerto Rico get transplanted, the Liver Committee could create a variance for Puerto Rico similar to the one for Hawaii, which allows blood type O livers recovered there to go to compatible candidates before being allocated to the continental US.

The Committee discussed how geographically isolated areas should be considered in changes to geography. In its discussion of this issue, the Geography Committee noted that members could put in screening criteria that they do not want offers from certain geographically distant places, so they would not receive those offers. One Committee member pointed out this already exists in that every program has screening criteria of how far they're willing to travel and that rules of allocation should be blind to what a program chooses to select as an offer. A Committee member noted the potential impact on discard rates if livers that would otherwise be allocated fail to be utilized because cold ischemic time accumulates. Another Committee member noted that discard rate is also dependent on program behavior, which may vary according to how risk averse a program is. The OPO Committee is working on a project of possible time limits to accepting or rejecting offers, which might address expedited placement and help with the discard rate issue.

Increased costs due to broader sharing might also become an issue, but there are challenges in assessing costs. The Operations and Safety Committee is currently doing a survey to gather data on Organ Procurement Organizations (OPO) practices, recovery practices, and some of the cost. Socioeconomics of minority populations might overlap with cost and efficiency challenges.

The MAC reviewed a draft of the recommendation to the Liver Committee. The MAC recommends that the Liver Committee extend the blood type O variance to Puerto Rico to protect against adverse impacts on high MELD/status1A candidates that would no longer receive regional offers. The MAC also recommends that the Liver Committee look at discard rates in the post implementation monitoring plan.

The reasons for the recommendations include reducing possible discards when removing regional share, treating Hawaii and Puerto Rico similarly due to the logistical challenges of being non-contiguous, and fully accounting for the impact to low SES and minority populations.

Next steps:

The recommendation will be distributed to the Liver Committee.

3. Socio-Economic Status (SES) and Access to Transplant

The Committee reviewed progress on a project to address limitations in access to transplant for low SES candidates.

Summary of discussion:

It has been challenging to narrow the focus of this project, given that many factors contribute to low socioeconomic status and challenges in accessing transplant. The Committee must decide what data to obtain and what measures should be focused on.

- One idea is to create a best practice document or website to be a resource for the community. For example, the RaDIANT study was a community study that had a social worker assigned to working with patients with low socioeconomic status. They determined how long it took with the social worker assistance for the patient to move from referral to listing and then how many patients got listed. This would be something similar to the COIIN study in that institutions would then have access to other institutions' best practices so they could implement those as well.
- Another idea was to heat map the U.S. among socioeconomic status groups and look at their access to transplant stratified by geography. The differences in access could serve to create a "best practices" resource based on institutions' practices that are most successful addressing low SES barriers in access to transplant. This resource could be distributed to help programs improve their low SES candidates' access to transplant. The heat mapping would be a starting point to see where disparities are throughout the country.

One place to start researching might be kidney living donors because more data is available on which institutions are better at helping low SES candidates' access to living donation. Zip codes would be the most granular data to obtain. Feedback is needed from the whole Committee on what type of additional data to be collected by UNOS would be most impactful.

The Committee agreed that this project will require multiple steps including collecting data, performing a survey based on results of the heat map, and then providing education to transplant centers dealing with SES candidates. The Committee discussed possibilities for the data request including:

- Whether geographical differences in access to kidney transplant on waitlist based on SES exist
- How the Committee should define SES
- Which organs to focus on
- Data that could identify candidates that move from referrals to listed and variability in center-specific referral data
- Any aggregate data on referrals

The Committee then moved forward with formulating a data request for:

- Kidney living donor and deceased to stratify by either living donor or deceased donor
- Five-digit zip codes
- Metrics to stratify by (BMI, transplant rate, wait list mortality)
- Ways to define SES (education level, insurance status, link to census data for income, Medicaid status)

Exploratory analysis could be done of the data: for example, how many Medicaid patients get living donor transplants and if that is different by Medicaid status.

Next steps:

The data request summarized today will be sent to all Committee members for comments or feedback. Next Subcommittee meeting will be on October 25, 2018 teleconference.

4. Review of Geography Frameworks

The Committee reviewed the Geographic Frameworks proposal that has been out for public comment.

Summary of discussion:

One member noted that although organs are considered a national resource, messaging and education often focuses on local donation, so there could be an opportunity for better alignment with education and messaging efforts. There was some concern expressed about the impact on small volume and rural programs with broader sharing. It is likely that changes to geographic allocation may create new vulnerable populations as well as impact currently vulnerable populations. Therefore, organ-specific committees should be aware of these potential unintended consequences while they work to develop new allocation policies.

Next steps:

A formal vote will not be taken, but Committee members can go on the OPTN site to comment. The Committee liaison will summarize the comments and submit a comment on behalf of the MAC on the OPTN website.

5. Spring Public Comment - MAC Engagement

The Committee discussed how it could help organ-specific committees consider and think through the potential impact of geographic changes on vulnerable populations.

Summary of discussion

MAC's charge is to consider aspect of organ procurement, allocation and transplantation with the potential to impact minority populations. The Committee provides input and

recommendations regarding ongoing efforts of OPTN/UNOS committees and Board of Directors to ensure needs of minority populations are being addressed.

The MAC thus far has reviewed liver modeling changes to provide a recommendation to the Liver Committee, made sure the checklist is being used in terms of modeling requests, and has drafted a memo to organ-specific committees reiterating the importance of considering minority populations in modeling requests and reviewing modeling analyses.

One opportunity for engagement is the MAC can review SRTR modeling from the lens of the minority populations to make sure the organ-specific committees are addressing the vulnerable population concerns in their public comment proposals.

Another opportunity for engagement is outreach to stakeholder groups. The goal is to make sure the different organizations (such as Association for Multicultural Affairs in Transplantation) that represent vulnerable populations are engaged in the conversation. MAC could identify those organizations and reach out to them to make them aware of the changes that are going on so they can provide their feedback. MAC could also then follow up to make sure they are staying engaged.

MAC has the opportunity to join other committees' calls from October to December as observers to gain insight about each committee's decision making process and help in understanding the potential impact of modeling.

Next steps:

The MAC will continue to engage with organ-specific committees to ensure that the potential impact of geographic changes in allocation on vulnerable populations is duly considered.

6. MAC Checklist

The Committee reviewed feedback on this resource from other committees and its utilization going forward.

Summary of discussion

Committee members agreed that in order to get people thinking about the minority populations, the checklist needs to be as easy as possible. The Committee also reviewed a memo directed to organ-specific committees to ensure consideration of vulnerable populations during the policy development process, especially with the expedited timeline of the geography projects.

The Committee discussed that when the OPTN does not collect data on certain populations, it can be challenging for Committees to identify the potential impact on these populations. Potentially these Committees could use guidance from the MAC during these discussions. A MAC member could join committee calls discussing vulnerable populations to help guide discussion about how potential populations could be impacted. There was discussion about whether the checklist could be shortened even further. One Committee member suggested a bare-bones one-page checklist and a separate document with the instructions and examples. The Committee reviewed the memo to accompany the checklist and approved it to be sent out.

Next steps:

The memo will be sent to organ-specific committees.

Upcoming Meeting

- October 10, 2018