

**OPTN/UNOS Minority Affairs Committee
Meeting Minutes
May 21, 2018
Conference Call**

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Introduction

The Minority Affairs Committee (hereafter, the Committee) met via Citrix GoToTraining teleconference on 05/21/2018 to discuss the following agenda items:

1. MAC News Update
2. Vulnerable Populations Checklist Update & Highly Sensitized Work Group Update
3. Improving Committee Structure Update
4. New Project: Disparity in non-contiguous United States (US)
5. New Project: Socio-Economic Status & Access to Transplant

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

1. MAC News Update

The Committee received an update on publications related to A2/A2B to B utilization in kidney allocation and reducing racial disparities in access to transplant. The A2/A2B paper examined the impact of the kidney allocation system (KAS) on minority populations' access to transplant. The paper found there were still significant discrepancies for African Americans' access to transplant, and concluded that the allocation system needs to be approved to address these discrepancies.

The second paper focused on working as a community to reduce racial disparities. Committee members were informed where to find the abstracts online and through the Committee SharePoint site.

2. Vulnerable Populations Checklist Update & Highly Sensitized Work Group Update

The Committee reviewed feedback from the Pediatric Committee, Histocompatibility Committee, POC, and UNOS staff related to the vulnerable populations checklist.

Summary of Discussion

One of the comments the Committee reviewed was to consider adding highly sensitized candidates as a vulnerable population. A representative on a Kidney Work Group reported that this suggestion stems from current work to address inequity for highly sensitized candidates. Current prioritization of highly sensitized candidates is based on whole number cPRA (99% vs 98%, e.g.). However, this current system misses the nuance between cPRAs between whole numbers, treating a cPRA of 98.75% the same as 98.01%.

A Committee member on the Kidney Work Group reported that the Work Group is getting data related to highly sensitized candidates. The Work Group feels there needs to be a steady increase in priority instead of priority based on whole number cPRA. The Work Group's efforts are important to the Committee because highly sensitized candidates are correlated with sex, ethnicity and sickle cell disease.

Next Steps

The policy liaison will send out the vulnerable populations checklist for final review to the Committee.

3. Improving Committee Structure Update

The Committee also received an update about an Executive Committee project to improve committee structure. For that project, a proof of concept in the fall will test new tools for engaging the community and committee members.

Summary of Discussion

Committee members expressed support for the proof of concept and appreciated that the Executive Committee listened to the Minority Affairs Committee and other members of the community in their concerns about the original concept paper. The Committee asked about the metrics which will be used to measure the success of the proof of concept. These are still being developed by the Executive Committee, working with the committees that are piloting the concept. The proof of concept will be for the fall public comment cycle, from July 1 to December 30, 2018.

Next Steps

The Committee will continue to monitor the effects of the proof of concept throughout the fall.

4. New Project: Disparity in Non-Contiguous United States (US)

The Committee discussed a new project to examine whether there exists a disparity in the allocation of organs for the non-contiguous US, specifically Puerto Rico and Hawaii.

Summary of Discussion

There is concern that non-contiguous US states and territories (specifically, Puerto Rico and Hawaii) export more organs than they import, creating a disparity in organ distribution. The Committee identified key elements of a data request to determine whether this problem exists. In particular, the Committee discussed looking at pre- and post- KAS data, to see if the emphasis in KAS on national sharing had an impact on non-contiguous allocation. The Committee agreed, however, to look at all organs for the non-contiguous US, not just kidney.

Another important factor in assessing disparity is access to transplant. Therefore, the data request will include analysis of waiting list mortality in Puerto Rico and Hawaii compared to the rest of the US. A Committee member suggested looking at kidney waiting time, which has certain challenges, but may be included in the data request. The data request may limit the assessment of Puerto Rico to a time prior to Hurricane Maria, which had a significant impact on Puerto Rico that could influence the data analysis.

The Committee determined that another important factor to include in the data request is assessment of the quality of organs offered, using Kidney Donor Profile Index (KDPI). The data request should also look at graft and patient survival. A Committee member suggested looking at the rate of Public Health Service (PHS) increased risk organs to see if that's why centers decline an organ. The research liaison will see if this is possible; it may be a very small sample to analyze. Another Committee member suggested looking at Bermuda and Alaska as well as Puerto Rico and Hawaii, although Bermuda and Alaska do not have transplant programs on site. The Committee member noted that Bermuda has a large African American population that could be impacted. The research liaison will look into whether the data request can assess disparity in allocation for areas without a transplant program.

Next Steps

The research liaison will write a data request based on the Committee's discussion; the data request will be submitted within two weeks of the call. The Committee will review the data analysis during its in-person meeting in September.

5. New Project: Socio-Economic Status & Access to Transplant

The Committee discussed a new project related to the impact of socio-economic status on access to transplant.

Summary of Discussion

The Committee reviewed a current report, the Equity in Access Report that is published quarterly and reviews the potential impact of different factors on access to transplant for patients on the waiting list. The research liaison clarified that length on the waiting list and whether the patient was active or inactive was accounted for in the model. The data related to patients referred to transplant is not collected by the OPTN/UNOS, but there are other external data sources that look at this data. There are opportunities that exist for improving the inclusion of external data sources ("proxy" data) for OPTN/UNOS Committees.

The Committee looked at current UNOS forms for collecting data, and reviewed the data currently collected by the OPTN.

Next Steps

The policy liaison will send an email asking for volunteers to join a subcommittee to further discuss opportunities for addressing concerns about data integration and socio-economic impact on access to transplant. The email will include a copy of a UNOS transplant form, for Committee members to review.

Upcoming Meetings

- July 16, 2018 (teleconference)
- September 17, 2018 (Chicago, IL)