

**OPTN/UNOS Minority Affairs Committee
Meeting Minutes
January 22, 2018
Teleconference**

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

Introduction

The Minority Affairs Committee (MAC) met via teleconference on 1/22/2018 to discuss the following agenda items:

1. Opening Remarks and Welcome
2. Public Comment Presentations: Improving Committee Structure and 2018-2021 Strategic Plan
3. Active Projects Update
4. Closing Remarks

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

1. Opening Remarks and Welcome

Summary:

Spring public comment proposals are up for comment currently and available through 3/23.

A committee member recently collaboratively published a paper tracking the magnitude of living donor kidney transplantation disparity over time. It has increased for black and Hispanic candidates making it to the waiting list. There are plans to disseminate best practices to increase living donation, especially at dialysis centers, to help to mitigate this disparity in minority communities. The paper can be found on the MAC SharePoint site.

Another committee member is working with the American Society of Transplant Surgeons (ASTS) to publish a paper on the effects of new KAS (Kidney Allocation System) on minority communities.

MAC responses to public comment will be compiled by staff and officially submitted to be posted to the Public Comment website.

Staff reviewed Board meeting actions.

MAC will hear six Public Comment presentations from sponsoring committees and submit comments on behalf of the committee. Individuals are encouraged to submit individual public comments on the presentations, in addition to the MAC compiled comment.

2. Public Comment Presentations

- a. Improving Committee Structure

Summary:

Please see the Public Comment website for proposal and summary.

Staff will take roll call of specific questions being gathered in a new pilot to better understand public sentiment.

Summary of Discussion:

The Chair is not in favor of this proposal because the MAC will lose their ability to work on their own proposals. An important part of equity is having an independent voice. The change in structure is too immediate with no transition period when it starts in 2019. How will individuals be identified to lead projects? The committee recognized that it is important to open the committee structure to additional viewpoints from the transplant community. However, the overwhelming sentiment was that UNOS would lose its champion for equity.

A member commented that flexibility in bylaws to name only the key committees is important. Why it is necessary to distinguish between subject committees who would sponsor public comments versus expert councils who would only suggest ideas and do not sponsor public comments? It is to manage workload and for the expert councils to provide ideas (and why) to subject committees. The POC and Executive Committee assigns work, which is what we do already. The bullet is to manage the expectation of those serving on committees. Finding true subject matter experts to serve extends beyond the reach of the regional representatives.

Another committee member commented that while it is important to bring in more perspectives, it seems like a consolidation of power. Who on the council will be a Board representative? Staff explained that the Board members are NOT representing councils. The Board members are there to hear the perspective and represent the perspectives of the councils and committees at the Board meetings.

Is there anything that precludes an ad hoc member with expertise in a specific subject serve on a council? Why revamp the system? Correct, we do that right now. The En Bloc Kidney proposal collaborated with non-committee doctors from high volume en bloc centers. Experts are often sought outside of committee structure. The new structure would allow for a stronger voice because the experts are representing a larger group or perspective.

Staff conducted a roll call asking committee members to choose options from four specific sentiment questions. This is a pilot for public comment. Answers will not be put on the OPTN website.

- 1) What is your opinion of this concept?
- 2) The proposed changing in OPTN Structure allows for greater opportunity for participations by the transplant community.
- 3) The proposed change in OPTN committee structure strengthens your voice in the policy making process.
- 4) Do the proposed expert councils and subject committees capture all perspectives needed in the policy making process?

b. 2018-2021 Strategic Plan

Summary:

Please see the Public Comment website for proposal and summary.

Summary of Discussion:

A committee member asked if there will be surveys of members to gather qualitative feedback to complement the quantitative measures of progress. There are surveys already periodically planned and these goals are also tied to the personal goals of the CEO. The committee member stressed that this plan is not just about the numbers.

Measuring programs against other programs is helpful. Will rates of living donors be compared against living donor transplants? There are worthy efforts, but UNOS only has the ability to

pursue certain policies to create metrics. UNOS produces educational offerings for living donation, for example, but cannot create policy for centers to measure this.

Staff conducted a roll call asking committee members to choose options from three specific sentiment questions. This is a pilot for public comment. Answers will not be put on the OPTN website.

- 1) What is your opinion of this concept?
- 2) Do you think the OPTN strategic plans contains the right measure to assess progress on the strategic goals?
- 3) Staff will email committee members to select the priority five of twelve strategic initiatives.

3. Active Projects Update

a. NonA1 Guidance Webinar

Summary:

Staff reported that the webinar to spotlight successful non A1 programs is in production and it will be ready in March. This complements the nonA1 Guidance passed by the Board in December. If anyone else would like to contribute, please email the committee liaison. Another update will be given in March.

b. Committee Checklist Project

Summary:

The Committee reviewed the major populations included in the Checklist for all POC approved projects, as determined by the workgroup. The checklist document will list all major minority and vulnerable populations for POC approved projects to consider in the proposal development process. A complete draft document will be available for full committee review at the March in person full committee meeting.

The checklist will be part of a “toolkit” for committees and will include slide template for public comment presentations and the checklist document. This will be shared with the committees after the full MAC reviews it in March.

Summary of Discussion:

Should this list include children since there is a committee for this? This is a good question and the workgroup will discuss this more at the next meeting this week. This should be a checklist for the staff and committee for analyses and the Pediatrics Committee may already do this. While the hope is the committees will review data, the MAC cannot require it. It should encourage committees to be proactive.

4. Closing Remarks

Summary of Discussion:

The Vice Chair requested all MAC members come with at least one new (or more developed idea already discussed) for the March in person meeting. The committee will have a brainstorming session. Staff will send a reminder about submitting ideas in advance or at the meeting.

Upcoming Meetings

- March 5th, 8:30 am – 3pm CST, Chicago
- Future Meetings: TBD (May, July, September, November)