

**OPTN/UNOS Minority Affairs Committee  
Meeting Minutes  
July 24, 2017  
Conference Call**

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

**Introduction**

The Minority Affairs Committee met via Citrix GoTo teleconference on 07/24/2017 to discuss the following agenda items:

1. New Committee Member Orientation
2. Welcome and News
3. Policy Oversight Committee (POC) Update
4. Active Project Update: (nonA1) A2/A2B to B Kidneys Guidance
5. Regional Meeting Review
6. Discussion: New Projects

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

**1. New Committee Member Orientation**

Summary

Policy Staff provided an overview of the Minority Affairs Committee (MAC) charge and history, current members, and the policy development process.

Research Staff provided an overview of the research division, responsibilities and the role of data in policy making and committee data requests.

Scientific Registry of Transplant Recipients (SRTR) Staff provided an overview of roles and responsibilities and committee support. A brief explanation of inferential versus descriptive statistics was provided. No Committee requests for SRTR simulations have been submitted since MAC has existed.

Summary of discussion:

No questions from new Committee members were asked after each of the overviews. All slides from presentations can be requested from staff.

**2. Welcome and MAC News**

Summary:

The Chair welcomed new and returning members.

UNOS held a national media briefing to inform the public of the positive results of the Equity in Access Report. The MAC Chair and MAC former Chair were featured in a briefing, reporting on more equitable transplant rates and results for both the Hispanic and African American communities. It was reported in the Philadelphia Inquirer.

The Chair was also invited to provide the Hispanic results at the Texas Medical Center Hispanic Transplant Symposium on September 26, 2017. More information to follow when available.

### **3. Policy Oversight Committee (POC) Update**

An update was provided by the Vice Chair, representative on the POC.

#### Summary:

The POC assigns a project by strategic goal when considered by the POC. The MAC nonA1 guidance fall under the Equity in Access Goal. A chart indicating the current strategic alignment was shown. Goals one and two are currently over allocated in the approved project portfolio. This is also available on the OPTN website.

The POC has reviewed fifteen new project proposals since last June. In May, 23 ongoing projects were reviewed. The POC will review and consider the projects about to go to Public Comment on 7/31/2017 at the July POC meeting.

#### Summary of discussion:

No Committee discussion.

### **4. Active Project Update: (nonA1) A2/A2B to B Kidneys Guidance**

#### Summary:

The workgroup lead and MAC current Vice Chair reviewed the timeline and provided an update for this project, about to go to Public Comment. The Committee plans to send this to the Board for review in December 2017. The MAC will review all comments during the Public Comment period from July 21<sup>st</sup> through October 3<sup>rd</sup>.

#### Summary of discussion:

No Committee discussion.

### **5. Regional Meeting Review**

#### Summary:

Staff provided a review/list of all proposals going to Public Comment in July. All approved proposals will be found on the OPTN website by July 31<sup>st</sup>. All comments are monitored by Policy staff. A list of regional meetings was displayed. All regional representatives are expected to attend regional meetings. The nonA1 guidance proposal, sponsored by the MAC, will only be posted but not orally presented. Send any questions to staff.

Regional representatives are requested to review all materials, answer any questions at meetings and bring any feedback to Committee meetings.

#### Summary of discussion:

No questions or discussion.

### **6. Discussion: New Projects**

This was a continuation of the new project brainstorming session held at the MAC March 2017 meeting, led by the current Chair.

#### Summary:

The Chair reviewed the process of analyzing problems. Here are the questions that should be addressed:

- What problem are you trying to solve?
- Is this a problem the OPTN should be solving?
- What are some potential solutions?

- Is your committee the only committee that should be involved?

If there are committees focused on topics this committee wants to address, it should be given to another committee or should be a collaborative effort.

#### Idea: Project Checklist

This staff idea is to develop a checklist that all committees can use to report how minority/vulnerable populations are impacted, as committees work on projects. It can be used to consistently track impact. Race, gender, and age can be included in the equity checklist. This may be able to be included in the project form for each new idea. This would likely not need POC approval to be a project.

#### Summary of discussion:

One member asked if committees would be provided guidance on what to review. This is the idea that is being presented. The Chair requested that anyone interested in leading or participating in the project notify staff.

Another member asked if this would be sent to all committees to complete while they are doing data analysis or at a different point. This would be completed in advance of public comment and early in the project work. The Chair requested that committee members see project form.

One member commented that there is an impact assessment for each new project. What is included in this? Impact on minorities is not always consistently assessed before MAC hears presentations. Staff suggested that the Checklist can be completed right after POC approval, when Committee work is beginning.

#### Idea 1 (from March Meeting): Geographic Disparity

This idea can include review of distance from transplant center and time to transplant among all organs.

Is patient location recorded? Research staff reported that state and zip code are reported. Not all of the last 4 zip codes are obtained. Three articles referencing available data were sent to committee members to read before this meeting.

#### Idea 2 (from March Meeting): Barriers to Care

The idea is to examine income, education, ethnicity, followed by other barriers to care. Not much data is collected for this. Research reported that no income data is collected. Staff asked if this data would review those only on waiting list. Yes.

#### Idea 3 (from March Meeting): Non-English Speaking

This project may include obtaining patient access to nephrologists, creating hotlines for different languages, or creating non-English speaking public service announcements. The Chair is not sure this is an idea the committee can work on because primary language is not recorded data.

#### Idea 4 (from March Meeting): Race or Minorities

This idea would focus on increasing living donation, increase knowledge for post-transplant, or increase education about VCA skin matching.

#### Summary of discussion (ideas 1 through 4):

The chair recommended Idea 1 or 4 to pursue. One member preferred idea 1 since data is available from UNOS/OPTN and transplant centers. Another member agrees and commented some research has been done on kidney geographic disparity. Older literature should be reviewed. One idea can include giving points based on distance. Research staff suggested the

group define Geographic Disparity first. Miles traveled in certain regions are not as much as a hardship as in others. Zip code, but no specific address is recorded for candidates. One member suggested that crossing state lines should be captured, in addition to distance traveled.

#### Next steps

Please send volunteer interest to liaison for either the Checklist Project or the Geographic Disparity Project. At least five members for each group are requested. A member volunteered to lead the Geographic Disparity project.

Meetings will be set up as soon as this is approved by management.

Any other new committee ideas are welcome at any time. Send to staff or leadership.

#### **Upcoming Meetings**

- September 18, 2017
- November 20, 2017
- January 22, 2018
- March 5, 2018