

**OPTN Minority Affairs Committee
Meeting Minutes
August 17, 2020
Conference Call**

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

Introduction

The OPTN Minority Affairs Committee (the Committee) met via Citrix GoToMeeting teleconference on 08/17/2020 to discuss the following agenda items:

1. Update on the Continuous Distribution of Organs Project
2. SES Template Outreach Discussion
3. Review TAC Feedback
4. For Discussion Next Month: Align OPTN Policy with U.s Public Health Service Guideline, 2020
5. Other relevant proposals

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

1. Update on the Continuous Distribution of Organs Project

The Committee heard the OPTN Lung Transplantation Committee's request for feedback titled, *Update on the Continuous Distribution of Organs Project*.

Summary of discussion:

A committee member commented that they believe there is not currently a good proxy for mortality in lung allocation. The presenter informed the Committee that waitlist mortality and post-transplant mortality are both part of the proposed system. This member also commented that the subjective nature of the request for feedback and prioritization exercise could lead to bias or gaming. Another Committee member with lung background said that gaming is a valid concern, but often risky because if done incorrectly a lung patient could end up appearing too sick to survive after the transplant, resulting in a drop in their LAS score and their chances of being transplanted. Overall the committee thought the *Update on the Continuous Distribution of Organs Project* innovative, but is concerned about the lack of objectivity.

Next steps:

1. Members have been asked to participate in a prioritization exercise that will close on October 1, 2020.
2. The Committee will draft a public comment on the *Update on the Continuous Distribution of Organs Project* request for feedback and post it to the OPTN website after their September meeting.

2. SES Template Outreach Discussion

A group of members is drafting an outreach template for MAC members to use when asking stakeholder organizations for support and feedback on the revised *Data Collection to Assess Socioeconomic Status and Access to Transplant* proposal. Members were asked to sign up for outreach.

Next steps:

The SES outreach template will be available for MAC member use by next week. MAC members will sign up for outreach and report back with their progress at the September meeting.

3. Review TAC Feedback

MAC leadership presented ideas for revisions to the *Data Collection to Assess Socioeconomic Status and Access to Transplant* proposal to the Transplant Administrators Committee (TAC) on July 22, 2020. The Committee reviewed TAC's feedback from this presentation.

TAC Feedback:

- Did not support that all transplant hospitals collect household income as part of the psychosocial evaluation
- Asked about the possibility of this proposal including an educational element
- Asked what would be done with the data and requested a more solid post-collection plan
- A couple members thought that the income range revision would be a good compromise.
- A member reported that her center does collect household income from kidney candidates
- Concerns we've previously heard: 1) ZIP Code data use 2) Patients will not report accurately 3) Cannot collect data on candidates that are not yet listed

Summary of discussion:

Committee members asked MAC leadership about the TAC's sentiment towards the proposed revision ideas. MAC leadership reported that some TAC members favored the revision ideas while others did not. A committee member asked how the Committee would plan to rework the proposal to garner more support in the upcoming public comment cycle. MAC leadership stated the revised proposal could offer annual household income range (as opposed to one number) and provide an opportunity to indicate that the annual household income range is not known. They added that this compromise could make the data collected not as complete or accurate, but that the data could still be useful to the OPTN. MAC leadership believes that the recent social justice events could increase community willpower to support a proposal that analyzes access to transplant based on SES. A member suggested creating a "frequently asked questions" document to help the MAC answer some of the anticipated stakeholder questions.

Next steps:

4. For Discussion Next Month: Align OPTN Policy with U.S. Public Health Service Guideline, 2020

Committee members will read the *Align OPTN Policy with U.S. Public Health Service Guideline, 2020* proposal and come to the September meeting ready for a group discussion.

5. Other relevant proposals

UNOS staff informed the Committee of three other relevant documents currently out for OPTN Public Comment:

- *Guidance and Policy Addressing Adult Heart Allocation*
- *Guidance Addressing the use of Pediatric Heart Exceptions*
- *COVID-19 Emergency Policies and Data Collection*

Next steps:

The Committee can submit individual public comments on any documents out for OPTN Summer 2020 Public Comment until October 1, 2020.

Upcoming Meetings

- September 21, 2020 (Full Committee Teleconference)
- October 19, 2020 (Full Committee Virtual “In- Person”)

Attendance

- **Committee Members**
 - Juan Del Rio
 - Raquel Garcia-Roca
 - Lakeicha Gunter
 - Nicole Hayde
 - Christine Hwang
 - Reynold Lopez- Solar
 - Paulo Martins
 - Yesenia Mara- Coffey
 - Okechukwu Ojogho
 - Dolamu Olaitan
 - Tahaunty Pena
 - Wayne Tsuang
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Darleen Arrowood
 - Elizabeth Miller
 - Lauren Motley
 - Kelley Poff
 - Susan Tlusty
 - Kaitlin Swanner
 - Sara Rose Wells
 - Anne Zehner
- **Other Attendees**
 - Amishi Desai (Board Member)