

**OPTN Minority Affairs Committee  
Meeting Summary  
October 19, 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 10/19/20 to discuss the following agenda items:

1. Social Determinants of Health: Data Acquisition and Feasibility Study
2. SES Proposal Discussion
3. POC Update
4. New Project Ideas

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

### **1. Social Determinants of Health: Data Acquisition and Feasibility Study**

The Committee heard an update on the Social Determinants of Health (SDoH) project from UNOS research.

#### Summary of discussion:

A member commented that they had further questions about who the prospective third party vendors are and how their data would be successfully connected to OPTN data. This member voiced that the Committee's *Data Collection to Assess Socioeconomic Status and Access to Transplant* project will collect data directly from candidates making it the most straightforward method of acquiring patient-level data. Another member asked how data would be linked to patients. UNOS research responded that there are a variety of features that could be used for linkage such as name, date of birth, social security number, etc. This member also asked about the validity of the data and if similar methods have been used in other research. This member asked about the limitations that prevent UNOS from collecting patient addresses. UNOS research reported that the third party vendors feel confident about their abilities to collect addresses. They also confirmed that the SDoH project will continue to develop regardless of the socioeconomic status (SES) project's outcome.

#### Next steps:

The Committee will receive another SDoH project update in a few weeks.

### **2. SES Proposal Discussion**

The Committee reviewed outreach feedback received on the SES project from OPTN committees and stakeholder organizations over the past few months.

#### Summary of discussion:

#### Committee feedback:

A member reported that some of the feedback received on the SES revisions are concerns that the MAC previously addressed, such as that the data will not be used for listing. Members felt that some of the other expressed concerns were off topic ideas the MAC has not mentioned as revisions, such as the development of quotas.

Stakeholder organization feedback:

The Committee reviewed feedback from the American Society of Transplantation's Inclusion, Diversity, Equality and Access to Life (IDEAL) task force. A member voiced that the AST's suggestion to report whether a candidate is above or below the poverty line would not address the concern over the intrusive nature of the question because candidates would have to report their annual household income as one number. Reporting annual household income as one number is what the revisions to the SES proposal steers away from, in an effort to make patients feel more comfortable. A MAC member who is also on the IDEAL task force explained that this comment focuses on how the data will be recorded.

The Committee reviewed feedback from the Center for Biomedical Research/Research Centers at Minority Institutions. A member asked if the collection of patient addresses was possible in order to collect SES data on a census tract level. Members asked why patient address is not currently collected by the OPTN. UNOS staff responded that while the OPTN is not prohibited from collecting patient addresses, making this kind of data useful comes with technical and security challenges. A member suggested that if the MAC's SES proposal does not go to public comment, the OPTN should consider collecting patient addresses.

The Committee reviewed feedback from the Transplant Recipient International Organization (TRIO). A member reported that many of TRIO's expressed concerns are on issues the MAC has attempted to address and reiterate. Members discussed SES data uses at the individual level such as risk adjustment or interventions for low SES patients who may have poorer outcomes.

The Committee discussed how to address the expressed concerns and move forward. A couple members expressed that the Committee should continue its pursuit of the proposal. The Committee discussed sending the proposal to the Winter 2021 Public Comment cycle. It was decided that the Committee would wait until their November meeting to vote on this.

Next steps:

The Committee will present the SES proposal to the Policy Oversight Committee on Thursday November 5, 2020 and plan to vote on sending the proposal to public comment during the MAC call on November 16, 2020.

**3. POC Update**

The Vice Chair gave an update on the Policy Oversight Committee's work on the strategic policy priorities.

Summary of discussion:

There was no discussion.

**4. New Project Ideas**

The Committee discussed two prospective project ideas:

1. Analysis of waitlist removals during the COVID era
2. Analysis of patients who received a transplant during the COVID era

The projected timeline on data request findings for the selected ideas is January 2021. If the Committee wishes to pursue both of these ideas in one data request, the timeline for results will be extended.

Summary of discussion:

A member asked about the possibility of writing a manuscript for an academic journal in addition to an OPTN product (white paper/guidance document). UNOS research responded that the OPTN product must be the Committee's priority. They added that if the Committee wishes to produce a manuscript from the results of the data request, UNOS research can assist with the methods portion of the paper, but the Committee members themselves must take the lead on writing. UNOS research reported that the OPTN product would need to be completed before the development of a manuscript and that the manuscript's development is usually done over email, outside of OPTN committee meetings.

Some members voiced interest in idea number two, but acknowledged that idea number one has policy implications that are more clear. Members found the ideas to be interconnected and asked about the possibility of submitting a data request for both ideas. UNOS research responded that this is a possibility, but that the Committee would not receive results from this larger data request until further into 2021. A member suggested starting with a data request for idea number two, analyzing these findings, and then move onto a request for idea number one. A member mentioned that currently there would be more COVID data for analysis in January 2021 or Spring 2021. UNOS research responded that there is enough COVID data for analysis, but like any data request following a policy era, if the Committee waited to make the request there would be more data to analyze. Another member asked if it was a possibility to make a data request now and then update that request in a few months. UNOS research responded that this is a possibility and routinely done during analyses of policy impact. The Committee determined that they would submit a data request for both project ideas. A member of the SRTR reported that their organization has done some work with COVID data and offered to share this with the Committee.

Next steps:

The Committee will hold a separate meeting to make their data request to UNOS research.

**Upcoming Meetings**

- November 16, 2020 (teleconference)
- December 21, 2020 (teleconference)

## Attendance

- **Committee Members**
  - Stephen Gray
  - Nicole Hayde
  - Christine Hwang
  - Reynold Lopez-Solar
  - Paulo Martins
  - Yesenia Mora- Coffey
  - Okechukwu Ojogho
  - Dolamu Olaitan
  - Oscar Serrano
  - Wayne Tsuang
- **HRSA Representatives**
  - Jim Bowman
- **SRTR Staff**
  - Monica Colvin
  - Bryn Thompson
- **UNOS Staff**
  - Laura Cartwright
  - Craig Connors
  - Shannon Edwards
  - Alex Garza
  - Irene Kim
  - Elizabeth Miller
  - Lauren Motley
  - Andrew Placona
  - Susie Sprinson
  - Susan Tlusty
  - Ross Walton
  - Anne Zehner
- **Other Attendees**
  - Pono Shim (visiting board member)