

**OPTN Transplant Administrators Committee
Meeting Summary
March 11, 2020
Conference Call**

**Nancy Metzler, Chair
Susan Zylicz, MHA, BSN, RN, CCTC, Vice Chair**

Introduction

The Transplant Administrators Committee met via Citrix GoTo teleconference on 03/11/2020 to discuss the following agenda items:

1. Data Collection to Assess Socioeconomic Status and Access to Transplant
2. Continuous Distribution of Lungs Prioritization Exercise
3. Other Business

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

1. Data Collection to Assess Socioeconomic Status and Access to Transplant

The Chair of the OPTN Minority Affairs Committee presented on their public comment proposal regarding data collection to assess socioeconomic status and access to transplant. The proposal would require transplant programs to collect data on annual household income and household size to gain more insight on how socioeconomic status impacts transplant access.

Summary of discussion:

The MAC Chair noted that they have received common feedback across regional meetings that new fields add data burden on transplant programs. Other feedback includes that OPTN collection of these data is too intrusive. The MAC Chair noted that collection of these data is actually standard among health care organizations and the OPTN is behind the curve by not collecting this data. She noted that regions have also expressed concerns about the accuracy of self-reported data. The MAC Chair asked TAC whether annual household income and household size are the best data elements to collect to measure SES, and what barriers might exist to collecting and reporting this data.

A TAC member noted that this data will only be collected for people who make it to the waitlist, and the main problem is the people who are not getting access to the waitlist. The MAC Chair responded that there is also a disparity in access for low SES patients who have been added to the waitlist and acknowledged that this proposal will not address patients who do not make it to the waitlist. The MAC Chair noted that the Final Rule requires that the OPTN strive for equity in access and this is one attempt to ameliorate the disparities as the OPTN isn't doing much else to make progress in this area and this is a starting point. The OPTN doesn't have the right data to make progress in this area.

The MAC Chair asked whether they could collect other information. A TAC member suggested drilling down to zip code from patient data (which is not an option due to liability issues). The MAC Chair said they have done research using zip code as a surrogate for SES. The MAC Chair said their research shows that the selected criteria would be the best for research.

A TAC member described how just looking at income alone without looking at other resources and support systems, e.g. insurance access and fundraisers, doesn't show the whole picture, but asking more information would be a data burden.

Concern that requesting this information breaks down trust between the patient and the transplant program. Is the data going to be rich enough to give enough gain to compensate for this potential risk? Patients who do not understand how listing or allocation work may be concerned that transplant programs are trying to preference some patients over others.

Next steps:

2. Continuous Distribution of Lungs Prioritization Exercise

UNOS staff presented to TAC on the Continuous Distribution of Lungs project and an associated prioritization exercise.

Summary of discussion:

One member asked how broadly the exercise will be distributed. UNOS staff explained that the hope is to get the exercise out to the broader community but in the interim UNOS is seeking as much participation as possible from committee staff. The Chair noted that she would be worried that she would not know how to weight the attributes appropriately, not being familiar with lung transplant. UNOS staff explained that participants do not need to be lung transplant professionals to share their opinions on the value judgments. Another member expressed concern that the exercise may drive us to the wrong solutions if people do not really understand the definitions of the attributes. UNOS staff noted that the broader public will receive videos explaining the context around the proposal when they are invited to participate.

Next steps:

UNOS staff will invite TAC members to complete the prioritization exercise via email.

3. Other Business

The TAC Chair asked who is still available to attend TMF. Three members said they will still be able to travel. The planning committee does not intend to change the moderators at this point until it gets closer to the date as things are still shifting. One member asked about the possibility of live streaming. It may not be possible to do live streaming for sessions running concurrently and some organizations have spent up to \$60K to coordinate live streaming so it will just be up to UNOS to decide how to approach the changes. Consider communicating options for people so they know whether they should cancel their registrations or if there will be a live stream option. UNOS staff is keeping a running list of organizational travel bans and speakers who are no longer able to attend. The Chair has a travel ban herself and will not be able to attend. The team is reassessing how members can help as travel bans change, and how members could provide remote assistance.

Upcoming Meetings

- March 25, 2020
- April – Meeting Date TBD