

**OPTN Ethics Committee  
Meeting Summary  
May 20, 2021 11:00 AM – 12:00 PM ET  
Conference Call**

**Keren Ladin, PhD, Chair  
Andrew Flescher, PhD, Vice Chair**

## **Introduction**

The Ethics Committee met via Citrix GoToMeeting teleconference on 5/20/2021 to discuss the following agenda items:

1. Project Status Updates
2. Ethical Considerations of Continuous Distribution in Organ Allocation

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

### **1. Status Updates**

The Chair provided a status update on the *Revise General Considerations in Assessment for Transplant Candidacy*, which will go to the OPTN Board of Directors in June for their final approval.

The Chair also informed the Committee that the Policy Oversight Committee (POC) approved the *Transparency in Transplant Program Selection* project. The Ethics Committee will complete Phase 1 of this two phase project, with the goal of going out for public comment in January 2022 and to the OPTN Board of Directors for approval in June 2022. Phase 2 of this project will be completed by the OPTN Data Advisory, Minority Affairs, and Patient Affairs Committees.

#### Summary of discussion:

Committee members expressed excitement and gratitude for the collective hard work and diligence in evolving the *Transparency in Transplant Program Selection* project into what it is now.

#### Next steps:

UNOS staff will reach out to members that have expressed interest in participating on the Transparency workgroup. The Chair informed members that UNOS staff may reach out and request their participation in the workgroup based on their expertise.

### **2. Ethical Considerations of Continuous Distribution in Organ Allocation**

UNOS staff gave a presentation about the changes that will occur through the development and implementation of Continuous Distribution as an organ allocation framework. The presentation identified the changes in how existing factors will be measured, which attributes will be added, and which ethical principles are associated with each of the framework changes.

#### Summary of discussion:

A member inquired on how, other than geography, ethical principles play a role in improving utility? The UNOS presenter responded that, within a lot of the previously presented rating scales, the majority of that information is more operational or clinical. However, when it comes down to trying to achieve

multiple goals it's imperative to have an ethical viewpoint that balances equity and utility and will guide the organ specific committees.

From a pragmatic perspective, a member expressed concern about how Continuous Distribution will be used to address the quality of the kidneys being allocated, the impact of Continuous Distribution on long term outcomes, and the potential for patients to be relisted in the future. The member urged the necessity to look beyond one-year survival rates and ensuring the best organs are matched with the best patients. Ultimately, the member stated that the post-transplant goal should be to never have a patient relisted because their initial organ transplant failed and recommended the inclusion of this outcome in conversations surrounding Continuous Distribution. UNOS staff informed the Committee that as the OPTN transitions to a new organ allocation framework there are improvements being made within each organ system. For example, the OPTN Lung Transplantation Committee is extending their outcomes from one-year to five-year survival rates and including additional factors like CPRA, while the OPTN Liver Transplantation Committee is reworking MELD and PELD scores. As the community provides feedback on these developing frameworks, it allows for a more efficient transition to implement some of these changes simultaneously.

A member also critiqued the logistical and operational challenges associated with transporting different organs and the need to not treat the entire country uniformly. UNOS staff responded that in line with Final Rule requirements, allocation methods and costs will differ based on organ specific needs. The information within this presentation only reflects the modeling that has been completed for the OPTN Lung Transplantation Committee, however, kidneys are extremely different and thus will have very different scales. Additionally, UNOS staff added that the OPTN wants to get to the point where live weather and traffic data will be incorporated into the operational and logistical decisions but ultimately decided to build this framework out step by step to develop trust in the system.

A member called out the importance of not substituting the equity of one group for another, especially when balancing equity with utility.

A member saw issue with what the OPTN measures in comparison to what Ethicists would promote as the ideal outcome. Instead, the development of Continuous Distribution is an opportunity to consider what ought to be included in each factor and improve the system to collect the data that fulfills that. UNOS staff responded that the data presented was just an example and the member countered that the example falls short in that it only reflects the data that is presently collected. Ultimately, the member expressed that in order to obtain the ideal outcome we need to collect the data that will lead the OPTN to those outcomes.

#### Next steps:

The Chair urged members to reach out to leadership or UNOS staff with any further questions surrounding Continuous Distribution.

#### **Upcoming Meetings**

- June 17, 2021
- July 22, 2021
- August 19, 2021
- September 16, 2021
- October 21, 2021
- November 18, 2021
- December 16, 2021

## Attendance

- **Committee Members**
  - Aaron Wightman
  - Amy Friedman
  - Andrew Flescher
  - Colleen Reed
  - Earnest Davis
  - Elisa Gordon
  - George Bayliss
  - Giuliano Testa
  - Glenn Cohen
  - Keren Ladin
  - Mahwish Ahmad
  - Sanjay Kulkarni
  - Tania Lyons
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Bryn Thompson
- **UNOS Staff**
  - Eric Messick
  - James Alcorn
  - Laura Schmitt
  - Ross Walton
  - Susan Tlusty
- **Other Attendees**
  - Ehab Saad