

OPTN Ethics Committee

Meeting Summary

September 21, 2021

Conference Call

Keren Ladin, PhD, Chair

Andrew Flescher, PhD, Vice Chair

Introduction

The Ethics Committee met via Citrix GoToMeeting teleconference on 09/21/2021 to discuss the following agenda items:

1. Welcome and opening remarks
2. **Public Comment Presentation:** OPTN Lung Transplantation Committee – Establish Continuous Distribution of Lungs
3. **Discussion:** Weighing attributes in continuous distribution
4. **Public Comment Presentation:** OPTN Minority Affairs and Kidney Transplantation Committees – Reassess Inclusion of Race in Estimate Glomerular Filtration Rate (eGFR) Equation
5. Closing remarks

The following is a summary of the Ethics Committee’s discussions.

1. Welcome and opening remarks

UNOS staff provided an update on staffing, public comment sentiment, and a brief overview of Ethics Committee participation in continuous distribution development.

2. Public Comment Presentation: OPTN Lung Transplantation Committee - Establish Continuous Distribution of Lungs

Dr. Marie Budev, the Vice Chair of the OPTN Lung Transplantation Committee, presented the public comment proposal *Establish Continuous Distribution of Lungs*.

Summary of discussion:

A member expressed concern about the potential lack of representation in historic data, specifically with regard to groups who may not have access to transplant, and the data’s ability to accurately predict future outcomes in a continuous distribution framework. The presenter provided an overview of the Analytic Hierarchy Process (AHP) Exercise conducted and the revealed preference process that the Lung Committee underwent to include the voices of the transplant community. A member inquired about the gaps in using one and two year survival data to predict five year survival outcomes.

A member expressed concern about the potential for continuous distribution to inadvertently disadvantage minority groups with respect to equity in allocation and outcomes and suggested the Lung Committee review the data by various socioeconomic and psychosocial factors. The representative from the Scientific Registry of Transplant Recipients (SRTR) informed the committee that they conduct annual data reports that break down distribution of organs by race and ethnicity. A member suggested providing a graphic that breaks down that tradeoffs that occurred when the Lung Committee prioritized weighting one attribute higher than another.

A member suggested equalizing across life years when calculating the composite allocation score. This member felt indifferent about if more time would be saved pretransplant or posttransplant because the priority should be providing a patient with the maximum life years. UNOS staff informed the Committee that the balance of life years is depicted in the full policy. Alternatively, a member provided the patient perspective in stating that the weighting of waitlist survival was more important because it provided hope to patients.

Members discussed the change in exception timeline and agreed that it was appropriate to reduce the exception deadline from 7 to 5 days. The presenter provided additional context on allowing a candidate to proceed with an exception score while their appeal was under review and members did not have further comments.

Next steps:

UNOS staff will compile the feedback from today's conversation to develop the official public comment for the committee. If members have any additional questions or comments on the proposal, please reach out to UNOS staff.

3. Discussion: Weighing attributes in continuous distribution

Due to time constraints, this topic was not discussed and will be placed on the October agenda.

4. Public Comment Presentation: OPTN Minority Affairs Committees and Kidney Transplantation – Reassess Inclusion of Race in Estimate Glomerular Filtration Rate (eGFR) Equation

Dr. Martha Pavlakis, Chair of the OPTN Kidney Transplantation Committee, presented the cosponsored public comment item *Reassess Inclusion of Race in Estimate Glomerular Filtration Rate (eGFR) Equation*.

Summary of discussion:

A member highlighted the lack of transparency and autonomy patients face in not knowing if their doctor is using a race based or race neutral eGFR calculation. A member shared the practice of their center in using a race neutral calculation and feels that this change is something that is readily supported by the transplant community. Members discussed the education within the transplant community that would be needed to ensure equity and increase access to transplant.

A member highlighted the discrepancy in calculations used for pediatric and adult candidates wherein race is only factored in for adult candidates. This increased the complexity for young adults as they transfer from pediatric to adult classifications and their eGFR substantially changes. Overall, the committee is very supportive of a race neutral eGFR calculation.

Next steps:

UNOS staff will compile the feedback from today's conversation to develop the official public comment for the committee. If members have any additional questions or comments on the proposal, please reach out to UNOS staff.

Upcoming Meetings

- October 21, 2021
- October 29, 2021
- November 18, 2021
- December 16, 2021

Attendance

- **Committee Members**
 - Aaron Wightman
 - Andrew Flescher
 - Colleen Reed
 - David Bearl
 - Earnest Davis
 - Ehab Saad
 - Keren Ladin
 - George Bayliss
 - Glenn Choen
 - Lynsey Biondi
 - Melissa Anderson
 - Roshan George
 - Sanjay Kulkarni
 - Sena Wilson-Sheehan
 - Tania Lyons
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Bryn Thompson
 - Maryam Valapour
- **UNOS Staff**
 - Abby Fox
 - Elizabeth Miller
 - Eric Messick
 - James Alcorn
 - Kelley Poff
 - Krissy Laurie
 - Kristina Hogan
 - Laura Schmitt
 - Lindsay Larkin
 - Ross Walton
 - Sara Rose Wells
 - Susan Tlusty
- **Other Attendees**
 - Marie Budev
 - Martha Pavlakis