

OPTN Transplant Administrators Committee

Meeting Summary

September 28, 2022

Conference Call

Susan Zylicz, MHA, BSN, RN, CCTC, Chair

Jason Huff, MSN, RN, FNKF, Vice Chair

Introduction

The Transplant Administrators Committee (the Committee) met via Citrix GoTo teleconference on 09/28/2022 to discuss the following agenda items:

1. Welcome
2. Review Board Guidance, Guidelines, and Policy (Lung Transplantation Committee)
3. Modify Waiting Time for eGFR Calculations (Kidney and Minority Affairs Committees)
4. Transparency in Program Selection (Ethics Committee)
5. Closing remarks and adjournment

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

1. Welcome

The Chair welcomed the Committee members and the presenters of the public comment proposals.

Summary of discussion:

There was no further discussion by the Committee.

2. Review Board Guidance, Guidelines, and Policy (Lung Transplantation Committee)

The OPTN Lung Transplantation Committee Chair presented on a proposed policy change that aims to update the Lung Review Board guidance, guidelines, and policy for continuous distribution. The proposal includes operational guidelines that cover representation, responsibilities, and process. Additionally, it includes clinical guidance that reflects updates for pulmonary hypertension exceptions and policy changes that align requirements with other organ review boards.

The presenter explained the operational guidelines, clinical guidance, and policy changes outlined in the proposal:

- Operational guidelines
 - Representative of active lung transplant programs serve on review boards for a 2-year term
 - Immediate past chair of Lung committee serves as review board chair for a 2-year term
 - Nine reviewers are assigned to each exception request
 - Chair is voting member of review board and serves as liaison to the Lung Committee
- Clinical Guidance
 - Candidates with pulmonary hypertension meeting certain criteria may qualify for a higher allocation score
 - Programs may request waiting list survival and post-transplant outcomes exception scores to be at the national 90th percentile

- Updates current guidance to reflect replacement of lung allocation score with composite allocation score
- Policy changes
 - Removes language that is duplicative with operational guidelines
 - Changes timeline for second appeal from 14 days to 7 days
 - Aligns timelines to:
 - Make both first and second appeals the same
 - Promote consistency with lungs and all organs

The presenter asked for feedback on:

- Should the committee add information in the guidance on how to request a priority 1 equivalent score for pediatric candidates in the new allocation system?
- Should the Chair be a voting member of the lung review board?
- Is it clear how the appeal process works?
- Do lung transplant programs anticipate any barriers to participating in the new Lung Review Board or using the updated exceptions process?

Summary of discussion:

A member noted it would be very helpful to add info in the guidance on how to request a priority one equivalent score for pediatric candidates in the new allocation system. The presenter encouraged the Committee to review the educational materials that are available. There was no further discussion from the Committee.

3. Modify Waiting Time for eGFR Calculations (Kidney and Minority Affairs Committees)

The Vice Chair of the Minority Affairs Committee presented on a proposed policy change that aims to address waiting time modification for registered Black kidney candidates affected by race-inclusive estimated glomerular filtration rate (eGFR) calculations.

The presenter stated the proposal includes the following:

- Waiting time will be restored to registered Black kidney candidates whose waiting time was affected by race-inclusive eGFR calculations, and meet documentation and timeframe criteria
- Requiring documentation of either candidates' eGFR values for Black and non-Black candidates or candidates' eGFR with a race-inclusive calculation and a re-estimation of GFR with a race-neutral calculation
- A timeframe of a 365-day period to submit an eGFR waiting time modification

The presenter asked for feedback on:

- Do community members agree with the proposed eGFR waiting time modification pathway?
- Do community members propose an alternative eGFR waiting time modification pathway?
- Should programs be required to assess their waiting lists and submit eGFR waiting time modifications for affected Black kidney candidates?
- What kind of education resources would assist programs in participating?
- What potential unintended consequences or challenges should be considered during this proposal's development? Do these consequences or challenges outweigh the benefits of the proposed waiting time modification pathway?
- Are there other waiting time medication scenarios that the members would like the committees to consider?
- Does the community agree with the proposed scope, timeframe, and required documentation?

Summary of discussion:

Members vocalized concern about leaving this modification optional. Programs that are not up to date on changes and policy may not know they can make these modifications which could potentially disadvantage some candidates. This could decrease equity and access. The presenter agreed and stated these comments will be well received by the committees. A member asked if there is the ability of UNOS to pull a report that streamlines those who will need a modification. The presenter stating having a report is something that can be done by programs because the OPTN does not have data on what GFR calculation was used and does not have GFR values for all candidates. Members also suggested providing education to programs on how to efficiently pull the report of candidates that will be affected by this change. There was no further discussion from the Committee.

4. Transparency in Program Selection (Ethics Committee)

An OPTN Ethics Committee member presented on a white paper that aims to ensure patient autonomy and shared decision-making through the transplant process. The paper examined the distinction between information and data that would aid in patient decision making, the role patients should have in determining which information they are interested in, and the education resources that can be provided to ensure that patients understand the information provided. The OPTN Ethics Committee member explained the Committee found that the ethical principles of organ allocation support increased transparency, challenges that may arise when increasing transparency can be mitigated and should not deter centers from increasing transparency, and information ought to be provided in a way that is accessible and patient centered.

The OPTN Ethics Committee asked for feedback on:

- What factors are important to patients when selecting a transplant program?
- Do patients and transplant professionals think that it is important to share program specific listing criteria prior to transplant evaluation?
- What best practices have transplant programs developed for increasing transparency?
- Does the transplant community think this information, shared with patients, would strengthen the provider-patient relationship, and/or provide better care for patients?

Summary of discussion:

A member noted that depending on the organ, geographic proximity to programs leaves few options for where a patient should list. Patients are also affected by insurance plans, financial barriers, and clinical situation. The member voiced concern that the transparency of transplant centers that might best suit the patient for listing criteria might not actually be a viable option for the previous stated reasons and this could frustrate patients more. Another member noted that for pediatric lung transplant there are only eight programs to choose from, which provides limited selection. Members worry that providing patients with too much information may overwhelm patients and reduce the amount of information they retain. A member explained being transparent about program specific criteria can be difficult. Centers use broad criteria to prevent limiting themselves. There should be better education on the types of decisions patients will need to make when selecting a program. The member discouraged the requirement that centers would have to disclose legal information around center policy. The presenter responded there is not a recommendation to share whole selection criteria. She noted decisions are made on a combination of lots of complex factors that do not all need to be provided to potential candidates.

The member suggested programs share their outcomes on their website and make patient-friendly education materials rather than providing a large amount of detailed information. Members emphasized

that it is important to share the practices of a program, their acceptance data, and their criteria for listing a patient. The presenter asked if centers have a lower cutoff body mass index (BMI) than others do why those patients are evaluated. The Chair responded it depends on the status of the center. She asked is this center robust, are they trying to build the program and are more aggressive or is this center more conservative. She explained that so many factors go into deciding which patients to list.

A member questioned the notion that patients are unable to receive multiple initial evaluations and asked the presenter where that assumption is coming from. The presenter explained that this is her experience at her center. The member stated it is a misnomer that they can only be evaluated once. He suggested patients can argue with the payer about this and that his center performs multiple evaluations. The presenter noted this assumes patients have the time and resources to take off work to come to these evaluations. The member explained it is a large commitment to receive a transplant and patients need to be made aware of that.

5. Closing remarks and adjournment

The Chair and UNOS staff thanked the Committee members and presenters for their time and updated the Committee on in-person meeting details.

Summary of discussion:

There was no further discussion by the Committee.

Upcoming Meetings

- October 12, 2022: 8:30AM-2:30PM ET, in-person

Attendance

- **Committee Members**
 - Christopher Wood
 - Denise Neal
 - Erica Seasor
 - Jason Huff
 - John Gutowski
 - Joshua Gossett
 - Kavita Devairakkam
 - Laura O'Melia
 - Michelle James
 - Nancy Metzler
 - Rachel Detweiler
 - Sara Geatrakas
 - Sarah Madgwick
 - Susan Zylicz
- **HRSA Staff**
 - Megan Hayden
- **UNOS Staff**
 - Angel Carroll
 - Kristina Hogan
 - Kaitlin Swanner
 - Laura Schmitt
 - Lindsay Larkin
 - Robert Hunter
 - Taylor Livelli
- **Other Attendees**
 - Alejandro Diez
 - Marie Budev
 - Sena Wilson-Meehan