

**OPTN Board Policy Group
Meeting Summary
November 10th, 2022
Webex**

Irene Kim, MD, Group Lead

Introduction

The Board Policy Group met via Webex on 11/10/2022 to discuss the following agenda items:

1. Consent Agenda Items for December 2022 Board Meeting
2. Transparency in Program Selection (OPTN Ethics Committee)
3. Modify Waiting Time for Candidates Affected by Race-Inclusive Estimated Glomerular Filtration Rate (eGFR) Calculations (OPTN Minority Affairs Committee & OPTN Kidney Transplantation Committee)

Board Members gathered to discuss the two policy proposals from public comment that are slated for the discussion agenda at the December Board of Directors meeting. The following is a summary of the group's discussions.

1. Consent Agenda Items for December 2022 Board Meeting

Susie Sprinson, Board Relations Manager, presented the consent agenda items to the group. They were briefed on the different reasons a proposal is placed on the consent agenda or the discussion agenda. Characteristics of consent agenda items can be non-binding guidance, proposals that generated little concerns from regions, individuals, societies, or communities; proposals that generated concerns, but those concerns were addressed with post-public comment changes. Consent agenda items require little to no programming and little to no member preparation. Discussion agenda items are proposals that generated concern amongst several regions, committees, individuals, or other groups, that contain major changes to organ allocation order, contain substantial new data reporting requirements for members, and substantial IT programming.

Board members were reminded that they may move any proposals from the consent to the discussion agenda. Board members were asked to submit any proposed changes before November 30th.

2. Transparency in Program Selection

Keren Ladin, Ethics Committee Chair, presented the *Transparency in Program Selection* White Paper on behalf of the Ethics Committee. Dr. Ladin presented the purpose of the white paper, the paper's alignment with the strategic plan, an analysis of public comment feedback, and discussed the estimated implementation measures. The project aligns with the OPTN Strategic Plan to improve equity in access to transplants. After public comment, a fifth example was added to specifically address pediatric transplant candidates.

Summary of discussion:

Board Policy Group Leader, Dr. Irene Kim, asked how the data presented to patients differs from the data the SRTR provides. Dr. Ladin explained that the project was coordinated with the SRTR Consensus Conference; the SRTR collects a lot of this data but the data does not cover listing patients. The SRTR only collects data once a patient has been waitlisted. Dr. Kim asked if the white paper would serve as

guidance for patients to educate themselves on what to be aware of when choosing a transplant center. Dr. Ladin responded that providing advice to patients is outside the purview of the Ethics Committee; the committee purview is whether there is an ethical need to transparently make information available to patients.

A group member asked if the committee considered other ways to disperse information to patients other than the OPTN website. Dr. Ladin stated that this might be more within the purview of the Patient Affairs Committee (PAC) or the Data Advisory Committee (DAC), rather than the Ethics Committee. She expressed that these committees would be better suited to make this information more readily available to patients. A group member suggested an advocacy model so people could take this project on from an advocacy standpoint. Dr. Ladin explained that the goal of the committee's work is to make healthcare more transparent for the transplant community. Another group member commented that operationalization is going to be the biggest challenge for the paper. Dr. Ladin thanked the member for the comment and agreed.

3. Modify Waiting Time for Candidates Affected by Race-Inclusive Estimated Glomerular Filtration Rate (eGFR) Calculations – OPTN Minority Affairs Committee & OPTN Kidney Transplantation Committee

Martha Pavlakis, Kidney Transplantation Committee Chair, presented the proposal to *Modify Waiting Time for Candidates Affected by Race-Inclusive Estimated Glomerular Filtration Rate (eGFR) Calculations* on behalf of the Kidney and Minority Affairs Committees. The goal of the proposal is to provide an opportunity for Black kidney candidates who have been affected by race-inclusive eGFR calculation to obtain waiting time they would have otherwise earned had a race-neutral GFR calculation been used. The proposal would allow transplant programs with Black kidney candidates who were affected by race-inclusive eGFR calculations to request modifications to these candidates' waiting time. The project aligns with the OPTN Strategic Plan to improve equity in access to transplants.

Dr. Pavlakis detailed the points of alignment between the Kidney and Minority Affairs Committee's and discussed the details the committees are still working to find common ground on. At the time of the presentation, the committees were still working on establishing the scope of modification and how many patient notifications there should be. Dr. Pavlakis explained the analysis from public comment and the necessary efforts needed for implementation.

Summary of discussion:

A group member was concerned that if the policy were implemented for all patients, then the patients who this policy was created for may be overlooked. Dr. Pavlakis responded that the policy would only apply to Black kidney candidates and not all patients. The group member then asked Dr. Pavlakis to explain what the committee means by using a "broad rollout" of the policy. Dr. Pavlakis reassured the group member that others have questioned what a broad rollout entails, but explained that the policy acts as restorative justice for the original eGFR policy modification that was approved in June of 2022. A group member thought this would be challenging for transplant centers to go back and find GFRs from years before. They asked what the expectations were on how far back transplant centers should go to find a patient's old GFR score. They also asked what the expectation is in terms of holding programs accountable for the information. Dr. Pavlakis said that the committees hope transplant programs will do their best to notify their patients of the changes and how these changes may affect them. The group member commented that they thought it was important for the committees to provide the expectations to transplant centers so there is no disconnect.

A group member asked for more information about the 365-day timeframe. Dr. Pavlakis explained that the 365-day timeframe does not have to do with patients correcting their information, but serves as a

deadline for programs to evaluate their records and ensure they have analyzed their waitlists within 365 days. Programs must submit an attestation after 365-days verifying that they completed the evaluation. The group member said there should be details in the policy for patients, so it is clear to patients that the cutoff does not apply to them, but for hospitals to do their due diligence. UNOS staff explained that in the policy language the eligibility for the modification is not connected to a date and it is explicitly stated in the language. Another UNOS staff member noted that the committee will address this through educational outreach.

A group member asked what happens to patients who did not originally identify as Black at first because there was no benefit of identifying this way and wondered if people can alter their race. Dr. Pavlakis stated that programs will complete their calculations based on the self-identified race on patients' documentation. Another group member asked if they needed to notify patients who are part Black and who may benefit from the recalculation. Dr. Pavlakis explained that both committees agreed that there should be a pre-implementation letter sent to patients that these recalculations are taking place.

Next Steps:

The Kidney Transplantation Committee met three days prior, and the two committees are currently working to finalize their proposal. The final proposal will be distributed to the Board ahead of the December meeting. The group will meet in St. Louis on December 5th to discuss the proposal and share their sentiments and feedback about the proposals.

Attendance

- **Group Members**
 - Bryan Whitson
 - Christopher Woody
 - Ed Hollinger
 - Irene Kim
 - Jeff Orłowski
 - Jerry McCauley
 - Manish Gandhi
 - Mark Barr
 - Robert Goodman
 - Wendy Garrison
- **HRSA Representatives**
 - Adrienne Goodrich-Doctor
 - Frank Holloman
 - Shannon Dunne
- **UNOS Staff**
 - Anna Messmer
 - Betsy Gans
 - Carol Covington
 - Cole Fox
 - Kayla Temple
 - Kelley Poff
 - Kieran McMahon
 - Kim Uccellini
 - Kristina Hogan
 - Laura Schmitt
 - Lauren Mauk
 - Lindsay Larkin
 - Morgan Jupe
 - Rebecca Murdock
 - Roger Brown
 - Ross Walton
 - Sara Rose Wells
 - Stryker-Ann Vosteen
 - Susan Tlusty
 - Susie Sprinson
 - Tamika Qualls
 - Tina Rhoades
- **Other Attendees**
 - James Pittman
 - Keren Ladin
 - Martha Pavlakis