

**OPTN Board Policy Group
Meeting Summary
November 7th, 2022**

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Introduction

The Board Policy Group met via Webex on 11/07/2022 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. The group was briefed on why proposals are placed on the consent or discussion agenda. Characteristics of consent agenda items can be non-binding guidance, proposals that generated little concerns from regions, individuals, societies, or communities; and 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 among several regions, committees, individuals, etc.; 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 can move any policy proposals from the consent agenda to the discussion agenda and the deadline to do so is November 30th.

2. Transparency in Program Selection

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

Summary of discussion:

Dr. Flescher noted that the goal of the paper is to serve as a guidance document, not as policy, and for the guidance to serve as a resource of best practices for transplant centers to utilize. It was noted that the paper is great to serve as a framework for the transplant community but could cause some difficulties at small transplant centers who may not have the same resources as large transplant centers. Dr. Flescher commented that patients who are involved in the decision-making process for their transplant are better off psychologically throughout their experience.

The group discussed that creating additional resources for patients can help to improve equity. A group member noted that patients can make independent decisions when provided with additional resources. A group member asked what expectations a white paper sets for the community as opposed to the expectations or purview of a policy. Dr. Flescher explained that the Ethics Committee has worked to provide details on what may be enhanced by transparency, but has not created a policy.

A group member suggested the committee include the top ten questions a patient should ask a transplant center when searching for a good fit. They thought this could be an efficient way to provide insight and education to patients on what kind of questions to ask. It was noted that not all patients will be able consider multiple transplant centers, so the committee thought that providing these questions would not add benefit. It was noted that this could be an appropriate question for the Minority Affairs Committee (MAC) to consider. Another group member commented that even if the OPTN provided questions for the patients to ask, patients would still have an uphill battle to have these questions answered. Dr. Flescher agreed that providing questions to patients could be beneficial to patients and would pass along the feedback to the rest of the 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

Alejandro Diez, Minority Affairs Committee Vice-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 a 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 goal of improving equity in access to transplants.

Dr. Diez specified the points of alignment between the Kidney and Minority Affairs Committee's and discussed the details the committees are still working on. At the same time of the presentation, the Kidney Committee was meeting to discuss the final considerations and clarification points. Dr. Diez presented the analysis from public comment and the estimated time commitment for implementation.

Summary of discussion:

A group member commended the policy for being mandatory rather than voluntary. The group discussed restorative justice for Black kidney patients that were potentially disadvantaged by staying on dialysis longer than they should have or receiving a transplant from a deceased donor. Dr. Diez replied that this was not a topic the committees discussed. A member asked about re-transplantation, and Dr. Diez thought this would be an important question for the committees to consider in the future.

The group discussed the 365 day timeframe, including what would happen to patients who join the waiting list during the 365 day timeframe or if someone is waitlisted after the 365-day timeframe. Dr. Diez explained that any patient that is listed in present day is listed without a race-based variable and those patients will already be listed with the new GFR calculation. A group member then asked how transplant centers reassess a patient's waiting time if they were not on dialysis, noting it might be more difficult to appropriately modify their waiting time. Dr. Diez explained that the committees did not want to limit wait time modifications to the preemptive community. UNOS staff further explained that the 365-day timeframe in the policy refers to what would be required for transplant programs review. A patient's GFR could still be changed after the 365-day timeframe. Dr. Diez explained that the 365-day timeframe is how long programs have to update their records to correct patients wait times.

A group member said that if these modifications are performed correctly, then there could be more than 30,000 people affected by this change. UNOS staff commented that 490 hours have been incorporated into the implementation process to account for the communication needs, updating monitoring processes, and education. A group member asked if this was the only option the committees considered for wait time modification calculations. UNOS staff explained that committee members discussed the possibility of adding two years of waiting time to every patient that was affected but the committees did not think this was efficient or equitable. A group member noted that this work to correct wait times was a step in the right direction.

Attendance

- **Group Members**
 - Annette Jackson
 - Barry Massa
 - Clifford Miles
 - Daniel Yip
 - Earnest Davis
 - Jim Sharrock
 - Lloyd Ratner
 - Stuart Sweet
 - Valinda Jones
- **HRSA Representatives**
- **UNOS Staff**
 - Anna Messmer
 - Betsy Gans
 - Carol Covington
 - Cole Fox
 - Kelley Poff
 - Kim Uccellini
 - Kristina Hogan
 - Laura Schmitt
 - Lauren Parker
 - 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**
 - Alejandro Diez
 - Andy Flescher