

**OPTN Minority Affairs Committee  
Meeting Summary  
October 17, 2022  
O'Hare Hilton, Chicago, Illinois, Paris Ballroom**

**Paulo Martins, MD, PhD, Chair  
Alejandro Diez, MD, Vice Chair**

## **Introduction**

The OPTN Minority Affairs Committee (the Committee) met in Chicago, Illinois, on 10/17/2022 to discuss the following agenda items:

1. Public Comment Update & Vote: *Modify Waiting Time for Candidates Affected by Race-Inclusive eGFR Calculations*
2. Social Determinants of Health (SDOH) Data Request
3. Research Orientation

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

### **1. Public Comment Update & Vote: *Modify Waiting Time for Candidates Affected by Race-Inclusive eGFR Calculations***

The Committee discussed post-public comment recommendations for *Modify Waiting Time for Candidates Affected by Race-Inclusive eGFR Calculations*.

#### Summary of discussion:

##### Optional vs. Mandatory Modifications

The Vice-Chair noted that there was consensus across the regions during regional meetings to make the proposed policy mandatory. A member expressed that if the proposal is mandated, it is essential to understand the burden transplant programs may face, specifically around their capabilities and available resources to assess their waiting list. The Chair agreed that if this were to be mandated, it would require extra work, and some programs might not prioritize assessing their waiting list and submitting modifications. Another member stated that although there was regional support to make the proposal mandatory, there were some concerns about how this will be monitored.

*Does the Minority Affairs Committee support mandating modifications?*

Straw poll: Support- 15, Abstain- 0, Oppose- 0

##### Monitoring Modifications

A member asked what documentation would be monitored. The presenter replied that a recalculation of a candidate's eGFR value or a submission of lab results from Quest Diagnostics or LabCorp would provide support that a qualifying candidate's eGFR would have been lower at an earlier date if a race – neutral eGFR calculation had been used.

Another member asked if there would be an opportunity to track barriers to providing documentation. This member asked if programs would be penalized if they don't provide documentation. The Vice-Chair agreed that there might be some challenges in providing documentation and explained that it might be

unfair to penalize a program if they do their best to comply with the policy, but cannot obtain the supporting documentation required to modify their candidates' eGFRs. A member added that the Kidney Committee discussed the opportunity to utilize the UNOS Professional Education and Communications departments to help clarify messaging around documentation that will be required for submission.

A member noted that if eGFR modifications are mandatory for programs and the OPTN does not have a way to monitor for compliance, it will be impossible to know if a program decides not to participate. The member further explained that this would be a problem because there would be no action to compel the program to comply with policy. Furthermore, the member suggested consideration of the actions UNOS could take to assist centers with compliance.

UNOS staff clarified that the purpose of the attestation documentation is for programs to attest that they have assessed their waiting list and submitted complete eGFR modification requests, with required documentation, for all potentially affected candidates. If the OPTN does not receive an attestation from a program, that program is not considered compliant with OPTN policy. A member suggested that education on the process should be developed for transplant programs.

Another member asked how the public and patients will be notified of this policy change. This member continued, explaining that instead of notifying only Black patients, all kidney patients could receive a notification. The Chair suggested that if the transplant program cannot obtain lab documentation, the patient should be given the opportunity to self-advocate by obtaining their lab results and communicating with their transplant programs to submit their results to the OPTN.

A member asked what the transplant program is attesting to. The presenter replied that the attestation would state that the transplant program has assessed its waiting list and completed its modifications.

A member asked how many patients are potentially impacted by a race-inclusive variable. The presenter answered that we have data on the total number of African American patients but not how many patients were affected using a race-inclusive eGFR. UNOS staff clarified that starting on July 27, 2022, the OPTN required all programs to use a race-neutral eGFR. The challenge is that the OPTN does not collect information regarding if a program used race-inclusive or a race-neutral calculation. Therefore, if implemented, assessment of waiting lists would be the responsibility of the transplant program to understand the impact on African American patients.

A member stated that at their program, the population of patients affected might be smaller than expected. A member asked about the best way to monitor compliance. The presenter replied that a best practice could include transplant programs maintaining documentation supporting the review of their waiting lists. Another member asked if the attestation could be made public on the UNOS website. The presenter agreed that this idea could be considered.

A member emphasized that it is essential that programs know how to review their waiting lists. The presenter asked if developing communication and educational materials for programs would be helpful. The Committee agreed.

A member asked what would happen if a transplant program did not meet the requirements by the deadline. The presenter responded that the policy would state that if a program does not submit attestation per the policy timeline, then the program will not be in compliance with the policy. This will allow the OPTN to reach out to the program and take the next steps.

*Does the Minority Affairs Committee support that programs must submit documentation and attestation documents to the OPTN?*

Straw poll: Support - 15, Abstain- 0, Oppose- 0

#### Scope

A member asked if programs would have the option to include dialysis candidates instead of their inclusion being a requirement. The presenter stated that the Kidney Committee also expressed this idea.

A member explained that as a patient's kidney renal function declines, they can be placed on a transplant list before they need to go on dialysis. This member continued that this preemptive population is a small compared to the number of individuals on the waitlist. The dialysis population is relatively larger.

A member pointed out that the original intent of the proposal was to provide equity to the population impacted by a race-inclusive variable, such as preemptively listed Black kidney candidates. Candidates on dialysis who were referred late may not have been affected by a race-inclusive variable but instead by a late referral. A late referral may not be due to a misapplication of the formula but instead due to a lack of health care or access to a nephrologist. The member expressed that the dialysis patients who were referred late are a separate issue from preemptive patients impacted by a race-inclusive variable. Therefore, including dialysis patients who were referred late does not align with the original intent of the proposal. The member expressed that they would recommend the limited scope to include only preemptive African American patients. If the Committee determines they should include dialysis candidates in the scope, this may disenfranchise individuals who may not gain time through this formula, such as Hispanics or individuals in rural areas.

Another member stated that the Committee can't fix all the inequities; however, as programs assess their waiting list, hopefully, it may become more apparent to them which populations are being listed preemptively versus those listed using dialysis criteria. A member replied that although there may be other inequities, the purpose is to fix the injustices of individuals impacted by a race-inclusive calculation. A larger conversation is needed to address other disparities, such as late referrals and inequities in healthcare. In the meantime, we should address the issue at hand and do what is right, which is to include both preemptive and dialysis patients within the scope. The Chair stated that if we limited the scope to preemptive patients only, it would benefit a small number of candidates.

*Does the Minority Affairs Committee support preemptively registered and dialysis candidates to be included in the scope?*

Straw poll: Preemptive - 4, Both -10, Abstain-1

#### Timeframe

A member stated that if we are going to make eGFR waiting time modifications mandatory, there needs to be an associated deadline for programs. Without a deadline, it appears to be more optional rather than mandatory. The Chair clarified that the 365 timeframe was proposed because programs with longer lists may experience a workload burden. The intent is to give larger programs sufficient time to review their list. Another member agreed that anything less than 365 days would be challenging for larger programs to meet a shorter deadline.

*Does the Minority Affairs Committee support a 365 timeframe?*

Straw poll: Support - 15, Abstain - 0, Oppose – 0

#### Candidate Notification

A member noted that notifications should be sent to all kidney candidates, in order to uphold transparency. A member suggested that UNOS could create a template that centers could use to notify their patients.

A member inquired if eligibility criteria are shared with candidates. If candidates are unaware of how they were listed, how would they know if they were impacted by a race-inclusive eGFR calculation? The member suggested including language within the notification about what qualifies a candidate. Another member indicated, including historical information regarding how we got to this point and the policy's purpose.

Another member emphasized that it is important to provide clear language about what is expected of the transplant program and the timeline for reviewing their list and notifying candidates. Providing clarity may give the community a sense that transplant programs are being held accountable. The notification should be standardized with specific criteria so that all candidates across the country are made aware of the policy. The Vice-Chair agreed, but noted that we should not provide programs with exact notification language and instead give them guardrails to help guide what the notification should look like. Another member asked who should receive the notification and what they should be notified about. The Committee agreed that the notification should be sent to all candidates.

A member asked if a candidate who meets the criteria to regain back waiting time will be notified. Another member noted that if we notify all kidney candidates of the change, we may need to notify all kidney candidates of their results. Members also inquired if a second notification should be sent out to candidates. Another member suggested that if candidates believe the policy impacted them, they should be able to self-advocate for themselves by obtaining lab results and submitting them to their transplant program. Another member suggested having a FAQ or a one-pager that helps explain these details.

A member suggested sending one post-notification that would be sent to all candidates instead of pre- and post-notifications. The post notification could include information about the new policy and how the policy could potentially affect kidney candidates. Also, the notification could include language that encourages the candidate to self-advocate. Additionally, this may help decrease the burden of transplant programs.

A member clarified that transplant programs would have a deadline to review their waitlist and submit their modifications. If a patient decides to self-advocate by reaching out to their nephrologist or primary care physician to obtain documentation stating they had a qualifying GFR, they may have the opportunity to do so regardless of the transplant program's deadline to submit their modifications. Therefore, the deadline is for the transplant programs and not the eligibility for the candidate. Another member noted that if candidates were determined eligible to regain wait time, the notification should include this information as well.

*Does the Minority Affairs Committee support that transplant centers will send a notification to all patients?*

Straw poll: Support - 15, Abstain- 0, Oppose- 0

*Does the Minority Affairs Committee support Modify Waiting Time for Candidates Affected by Race-Inclusive eGFR Calculations as proposed today?*

Vote: Support – 15, Abstain – 0, Oppose - 0

Next steps:

The MAC's *Modify Waiting Time for Candidates Affected by Race-Inclusive eGFR Calculations* recommendations will be discussed by the OPTN Kidney Transplantation Committee, who will also vote on policy language

## **2. Social Determinants of Health (SDoH) Data Request**

The Committee heard a data request on the SDoH from the UNOS research department.

### Summary of discussion:

A member suggested a future project could be working with the Data Advisory Committee (DAC) to obtain additional socioeconomic data to calculate the poverty line. Another member asked if the data was available through UNOS or another source. The presenter replied that the data was from a third party called Lexi Nexus.

A member noted that since location data is being collected, such as collecting zip codes, it may be helpful to create a map to see the distances candidates are traveling to the transplant program to understand gaps where no candidates are being referred.

A member noted that the study cohort is inclusive of data from 2020. This member asked if there was any indication that COVID impacted the data? The presenter replied that that was a limitation of the data.

A member inquired if this data applicable to children. The presenter replied that the data is limited to adults 18 or older. Lexus Nexus data is from various records so this data may not apply to children.

## **3. Research Orientation**

The Committee heard a presentation about the roles and responsibilities of the research team from the UNOS research department.

### Summary of discussion:

There was no discussion.

## **Upcoming Meeting**

- November 21, 2022

## Attendance

- **Committee Members**
  - Paulo Martins
  - Alejandro Diez
  - Christine Hwang
  - April Stempien-Otero
  - Ayana Andrews-Joseph
  - Jason Narverud
  - Nwamaka Eneanya
  - Niviann Blondet
  - Reynold Lopez-Soler
  - Wayne Tsuang
  - Anthony Panos
  - Steve Averhart
  - Christiana Gjelaj
  - Marcus Urey
  - Adrian Lawrence
- **HRSA Representatives**
  - Jim Bowman
  - Shelly Grant
  - Lauren Darensbourg
  - Monica Colvin
- **SRTR Staff**
  - Katherine Audette
- **UNOS Staff**
  - Tamika Watkins
  - Kelley Poff
  - Lauren Mauk
  - Rebecca Murdock
  - Tatenda Mupfudze
  - Carol Covington
  - James Alcorn
  - Sara Moriarty
  - Jesse Howell
  - Darby Harris
  - Roger Brown
  - Tina Rhoades