

**OPTN Minority Affairs and Kidney Transplantation Committees
Reassess Race in eGFR Calculation Workgroup
Meeting Summary
October 11, 2022
Conference Call**

**Martha Pavlakis, MD, Co-Chair
Paulo Martins, MD, Co-Chair**

Introduction

The Reassess Race in eGFR Calculation Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 10/11/2022 to discuss the following agenda items:

1. Public Comment Analysis & Discussion: *Modify Waiting Time for Candidates Affected by Race-Inclusive Estimated Glomerular Filtration Rate (eGFR) Calculations*

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

1. Public Comment Analysis & Discussion: *Modify Waiting Time for Candidates Affected by Race-Inclusive Estimated Glomerular Filtration Rate (eGFR) Calculations*

The Workgroup reviewed the public comment analysis: *Modify Waiting Time for Candidates Affected by Race-Inclusive Estimated Glomerular Filtration Rate (eGFR) Calculations* and discussed potential recommendations.

Summary of discussion:

Optional vs. Mandatory Modifications

The Co-Chair stated that public comment indicated widespread support for making the proposal mandatory. A member asked if the proposal was made mandatory, would it alleviate the burden on some transplant programs, as they would be required to assess their lists for potentially qualifying Black candidates. The Co-Chair replied that there have been ongoing discussions regarding the possibility of UNOS providing programs with a list of potentially qualifying candidates to alleviate some of the administrative burden. A member stated that mandatory modifications for all impacted patients would be more equitable than optional modifications.

Regarding monitoring options, a member said they favor that programs be required to maintain documentation. A member asked if the documentation would only be requested if the program is being audited on a site visit. A UNOS Member Quality department representative stated that eGFR waiting time modifications would not likely be flagged as part of a routine survey. Therefore, maintaining documentation would be considered the monitoring option with the least amount of OPTN oversight. The Co-Chair stated that they favor that programs should be required to submit an attestation document to the OPTN, as a higher level of monitoring should accompany a mandatory policy. A member asked what the attestation form would include. The presenter replied that there was a discussion about programs submitting documentation stating that they have reviewed their patient list and submitted modifications for potentially qualifying candidates.

A member stated that there is a lot of mistrust within the health system and the African- American community and suggested apologizing to the patients because a race-inclusive eGFR has impacted them.

The Co-Chair replied that OPTN policy does not state that programs should use a race-based eGFR calculation. The nephrology community should apologize because years ago, they accepted the race-based formula, which was based on a study with less than 200 Black/African-American participants. At that time, nobody asked why that small group of Black Americans would have had a better kidney function for the same creatinine and nobody assumed it was for any reason other than race. They did not look at diet or medication use, the effects of racism, where they lived, or other socio-demographic factors. Therefore, an apology is needed. However, if it comes from the OPTN, it may feel inappropriate, as out of all the stakeholders involved, the OPTN had the least to do with this because they never said which formula to use. There should be an open, honest, heartfelt statement about how Black people suffered from this is worthwhile. Another member expressed that the apology would be powerful coming from the National Kidney Foundation (NKF) and the American Society of Nephrology (ASN) and suggested that the Committees could endorse it.

A member asked if monitoring options could be a combination of program maintaining documentation and programs also submitting an attestation form to the OPTN. The presenter replied that if programs are required to submit the attestation form stating that they reviewed their list and have submitted the appropriate documentation for their candidate, then it would be expected that the program would also maintain that documentation.

Scope

A member stated that the proposal intends to correct a fallacy based on the use of an eGFR formula as it pertains to those pre-emptively listed candidates. The member explained that if the scope includes African American patients that were already on dialysis and then retroactively, there is a change in wait times to pre-dialysis initiation, that would disadvantage other populations that would not have the ability to have their waiting time modified. Including referred dialysis patients in the scope does not necessarily mean they were impacted by a race-inclusive variable but instead by a late referral, which does not align with the relevance of restoring wait time for candidates affected by a race-inclusive formula.

A member noted that as the Committees are working to fix the disparity for African American candidates impacted by a race-inclusive eGFR, it may appear that other populations are being disadvantaged. This member explained that there are multiple levels of disparity, and currently, there is an effort to focus on and fix the issue of Black candidates impacted by a race-inclusive eGFR calculations.

Another member stated that including preemptive and dialysis patients within the scope would have a greater impact. If the scope were limited to the pre-emptive patients only, it would be a smaller population; therefore, the effect would not be as significant. This is an issue of restorative justice, and the Committees should consider how impactful the proposal will be to the community.

Straw poll: Pre-emptive and dialysis candidates -7, Pre-emptive only- 2

Patient Notification

A member suggested that programs be required to notify their patients. Additionally, UNOS should consider developing a patient notification sample that could be used to guide programs. Members also discussed that African American patients listed at the program should receive the notification. Another member mentioned that patients should be able to advocate for themselves by letting the program know where they've had lab work done in the past if that information was not previously documented at their transplant center. Another member asked who would be responsible for sending patient notifications. The presenter replied that programs would be responsible for notifying their patients.

Timeframe

A member noted that patients have waited a long time for restorative justice, and the timeframe should be limited to 6 months for programs to assess their candidate lists and submit eGFR waiting time modifications. A member noted that larger transplant centers might need additional time to assess their waiting list and retrieve lab results. Therefore, one year is more feasible than six months.

Another member stated that if the proposal is mandatory, there should be accountability placed on the transplant programs to assess their patient waiting list. If there is no end date for programs to assess their list and submit their wait time modifications, it will allow programs to prolong this process. There should be an end date to increase urgency amongst transplant programs.

Straw poll: Six month timeframe- 4, 365 day timeframe- 5

Next steps:

These recommendations will be considered by the OPTN Minority Affairs and Kidney Transplantation Committees.

Upcoming Meeting

- TBD

Attendance

- **Workgroup Members**
 - Alejandro Diez
 - Arpita Basu
 - Amaka Eneanya
 - Beatrice Concepcion
 - Denise Alveranga
 - Irene Kim
 - Martha Pavlakis
 - Oyedolamu Olaitan
 - Paulo Martins
- **HRSA Representatives**
 - Jim Bowman
 - Shelly Grant
- **SRTR Staff**
 - Bryn Thompson
 - Monica Colvin
- **UNOS Staff**
 - Tamika Watkins
 - Kelley Poff
 - Lindsay Larkin
 - Lauren Mauk
 - Darby Harris
 - Jesse Howell
 - Kayla Temple
 - Krissy Laurie
 - Stryker-Ann Vosteen