

OPTN Patient Affairs Committee

Meeting Summary

August 16, 2022

Conference Call

Garrett Erdle, MBA, Chair

Molly McCarthy, Vice Chair

Introduction

The OPTN Patient Affairs Committee (the Committee) met via Citrix GoTo Meeting teleconference on 08/16/2022 to discuss the following agenda items:

1. Public Comment Review: Modify Candidate Waiting Time Dates Affected by Race-Based Estimated Glomerular Filtration Rate (eGFR) Calculation
2. Debrief: SRTR Consensus Conference
3. OPTN Policy Oversight Committee-reviewed projects

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

1. Public Comment Review: Modify Candidate Waiting Time Dates Affected by Race-Based Estimated Glomerular Filtration Rate (eGFR) Calculation

The Committee provided feedback on the OPTN Kidney Transplantation and Minority Affairs Committees (the sponsoring Committees) public comment proposal, *Modify Candidate Waiting Time Dates Affected by Race-Based Estimated Glomerular Filtration Rate (eGFR) Calculation*.

Summary of discussion:

The Committee expressed interest in the details regarding the timeline of this proposal and implementation as well as communication to patients. The Chair asked how compliance will be measured. Staff stated that the proposal outlines the monitoring plan for the proposed optional pathway, and the monitoring plan may change if the Committees change the proposal from an optional pathway to a mandatory requirement. The Chair asked whether the wait time modification could be transferred between transplant programs if a patient changes care. Staff stated that policy currently allows waiting time to transfer between transplant programs, so this would apply to any waiting time added through the proposed pathway as well.

The Chair asked how many patients could be impacted by this proposal. The presenter responded that potentially every African American kidney transplant candidate on the waitlist could be impacted. The presenter stated that every African American kidney transplant candidate on the waitlist would have a pathway to gain more time with how the proposal is currently written, except for someone who never had labs prior to the initiation of dialysis. The Chair asked if that is a common occurrence. The presenter stated it is not common, but they have experienced situations where patient did not have labs prior to the initiation of dialysis.

A member stated that in a regional meeting, the answer to how many individuals would be impacted by this proposal was different. The member stated that this is a critical issue and suggested that the answer needs to be aligned regarding the potential impact on transplant candidates to understand the urgency. The presenter responded that the proposal is not narrowly defined which leaves a broad interpretation,

but will take that feedback to the sponsoring Committees. Staff added that the OPTN does not collect information on transplant candidates who were or were not listed with a race-inclusive eGFR, which makes determining the number of individuals impacted difficult.

Members noted that the slides presented to PAC were slightly different from the slides presented in the regional meetings. Staff clarified that a standard set of slides are used in regional meetings for consistency and the slides were updated for PAC to respond to questions and feedback that members submitted in advance, but that in general the content is the same. The member stated that the candidate's eGFR value with a race-inclusive calculation and re-estimation of GFR value with a race-neutral calculation should be the primary required documentation.

A member expressed concern that 365 days may not be sufficient for large volume transplant programs to review the documentation for all transplant candidates and submit eGFR waiting time modifications. The member stated that region 4 has around 10,400 African American kidney transplant candidates, and transplant programs will be inundated with the proposed timeframe. The presenter stated that the Committees opted for the 365 day timeframe because they were concerned that an open ended timeframe would cause transplant programs not to attend to it, and patients would suffer in the absence of receiving accumulated waiting time. Another member stated an opposing view, stating that 365 days does not give the impression that this is an urgent matter. The member suggested that if this is a burdensome process, transplant programs should hire more staff to accomplish it. The member stated that any transplant program that used a race-inclusive eGFR calculation should be obligated to recalculate, and notify the patients within a lot shorter timeframe than the proposed 365 days. The member emphasized there needs to be accountability. Another member agreed the proposed timeframe should be shortened. The member suggested six months or less. Another member expressed concern for a shorter timeframe because it may have unintended consequences which could lead to other downstream effects.

Several Committee members agreed that this proposal should be mandatory, not optional. Another member agreed and stated that if there is not mandate, then transplant programs will not oblige. The member added that even with a mandate, the transplant programs will do the bare minimum. The Chair suggested the sponsoring Committees consider existing types of processes to ensure accountability that could be applied to this proposal to ensure a mandatory requirement and participation.

A member emphasized that education and communication is necessary. Another member agreed that it should not be burdensome for a transplant program to send their patient a letter to inform them of this change.

A member asked if there will be a requirement to notify patients. The presenter stated that the current proposal does not propose such a requirement. Another member emphasized that patients should be notified. A member stated that a standard communication should be sent to every African American patient, every transplant program, and relevant societies and stakeholders. Another member suggested a grassroots effort in the community to ensure everyone is aware, including individuals who have not been able to access a provider or transplant referral.

Another member stated there are transplant referral patterns that disadvantage other black and non-Black populations. The presenter acknowledged the concern but noted that the Committees did not want the presence of other disparities to take away from their ability to address this disparity, so this proposal is intended to specifically correct the racial disparity emanating from the race-based eGFR calculation.

A member stated that this proposal may lead to equity in access to transplant but there is no way to know because the responsibility is being placed on transplant programs with hope they do the right

thing, instead of the OPTN doing the right thing. The member stated that the current proposal, with no mandate and a 365 day timeframe, does not emphasize the urgency or importance of this matter.

Next steps:

The Committee's feedback will be summarized and submitted to the sponsoring Committees for consideration.

2. Debrief: Scientific Registry for Transplant Recipients (SRTR) Task 5 Consensus Conference

Several Committee members attended SRTR's Task 5 consensus conference.

Summary of discussion:

Committee members that attended the Task 5 consensus conference noted the follow areas of interest:

- Risk adjustment
- Data tracking and insights
- Equity and access
- Subway analogy; An analogy used to visual the transplant experience, and the challenges and opportunities afforded by each stop
- Communication with patients throughout the entire transplant process
- How to promote similar discussion between the professional community and the lay community
- The differences in the work-up processes at transplant programs
- Qualifying events that may prohibit an individual from being listed for transplant
- Role of insurers; the friction between insurers seeking to help patients while patients encounter complexities related to cost of care and medication
- Issues with access to transplant
- COVID-19 and lack of information provided to patients
- Visual information for patients to understand the transplant processes for each organ
- Organ procurement organization (OPO) metrics and performance
- Patient-centric metrics versus decision making data

Next steps:

The Committee will continue to discuss areas of interest from the SRTR's Task 5 Consensus Conference.

3. OPTN Policy Oversight Committee-reviewed projects

The following projects are recommended for approval by the OPTN Policy Oversight Committee:

- Clarification of OPO Requirements for Deceased Organ Donors with HIV Positive Test Results, *OPTN Ad Hoc Disease Transmission Advisory Committee*
- Review and Update OPTN Histocompatibility Guidance and Policy with Current Practice, *OPTN Histocompatibility Committee*

Next steps:

The Committee will provide feedback to the OPTN Ad Hoc Disease Transmission Advisory Committee during the development of the proposal.

Committee participation is not expected for the OPTN Histocompatibility Committee's upcoming project.

Upcoming Meetings

- September 15, 2022 (Richmond, Virginia)
- October 18, 2022 (teleconference)
- November 15, 2022 (teleconference)
- December 20, 2022 (teleconference)

Attendance

- **Committee Members**
 - Anita Patel
 - Calvin Henry
 - Dana Hong
 - Garrett Erdle
 - Julie Spear
 - Justin Wilkerson
 - Kristen Ramsay
 - Lorrinda Gray-Davis
 - Molly McCarthy
 - Steven Weitzen
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
 - Megan Hayden
- **SRTR Staff**
 - Allyson Hart
 - Katie Audette
- **UNOS Staff**
 - Alex Carmack
 - Erin Parkhurst
 - Kaitlin Swanner
 - Kayla Temple
 - Kim Uccellini
 - Krissy Laurie
 - Lauren Mauk
 - Lauren Motley
 - Liz Fridell
 - Meghan McDermott
 - Rebecca Murdock
- **Other Attendees**
 - Martha Pavlakis