

**OPTN Minority Affairs Committee
Meeting Summary
August 18, 2023
Richmond, VA**

**Alejandro Diez, MD, Chair
Oscar Serrano, MD, Vice Chair**

Introduction

The OPTN Minority Affairs Committee (the Committee) met in Richmond, VA, on 08/18/2023 to discuss the following agenda items:

1. 6-Month Implementation Update: Modify Waiting Time for Candidates Affected by Race-Inclusive eGFR Calculations
2. Ethical Analysis of Normothermic Regional Perfusion, OPTN Ethics Committee
3. Workgroup Update: Refit KDPI without Race and HCV
4. Concepts for a Collaborative Approach to Living Donor Data Collection, OPTN Living Donor Committee
5. New Project Brainstorm & Open Discussion
6. WebEx Transition

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

1. 6-Month Implementation Update: Modify Waiting Time for Candidates Affected by Race-Inclusive eGFR Calculations

Decision #1: There were no decisions made by the Committee.

The Committee heard a six-month implementation update on [Modify Waiting Time for Candidates Affected by Race-Inclusive eGFR Calculation](#). The policy was implemented in January 2023 and requires transplant programs to assess their respective waiting lists and submit eGFR waiting time modifications for affected candidates.

The Committee discussed the following questions:

- What part of the process is your program currently in?
- Any new challenges or opportunities for improvement?
- Any encouragement or advice to share?

Data summary:

UNOS Connect Course Engagement

As of August 2023:

- 791 participants registered for the course.
- Of the 791 participants registered, 397 participants completed the course.
- Of the 791 participants registered, 65 participants are pending evaluation.

- Of the 791 participants registered, 208 participants are still in the process of completing the course.
- Of the 791 participants registered, 121 participants registered but have not started the course.

Modifications & the OPTN Waiting List

- 33% of the kidney waiting list is Black or African American.
- 25% of potentially impacted patients have received adjustments to their waiting time.

Summary of discussion:

A member asked for clarification on the adjustment of waiting time. Staff replied that once programs submit the candidate's modification form and supporting documentation, the supporting documentation will indicate the date on which the candidate had an estimated glomerular filtration rate (eGFR) less than or equal to 20 mL/min. Then, the Organ Center will backdate the candidate's waiting time to the original date.

A member shared that their program is medium-sized, comprised of 300-400 patients, and their African American population is 36-38%. Their program identified 126 patients who may have been affected and qualify for waiting time. Of the 126 patients, 76 have received waiting time back, and 22 patients have been transplanted. He added that their program has had support from their nurse coordinator, who has taken the lead on assessing their waiting list and participated in eGFR webinars to educate staff on how to assess their waiting list for eligible candidates. Furthermore, their program was able to accrue 167.3 years of waiting time to their list.

A member asked what would happen if a program does not meet the policy requirement by the deadline of January 3, 2024, and if there is support for these programs. Staff replied that if programs have not completed an assessment of their list by the deadline, the program will be considered not in compliance with OPTN [Policy 3.7.D](#), and the program will be reviewed and monitored by the Membership & Professional Standards Committee (MPSC). Staff added that the OPTN is beginning outreach efforts to contact programs that have not started and those that have started but have not submitted their attestation.

A member asked if there is a correlation between the quality of organs and receiving wait time back. The Chair replied that there is an indirect association. He explained that having an earlier qualifying date indicates that the patient has more years on the waitlist, and by having more years on the waitlist, the patient has more points. When the match is run, that patient would be high on the match run, allowing them to go into different sequences based on the kidney donor profile index (KDPI). Another member clarified that if a patient is high up on the match run, they will receive access to an organ before the other patients below on the match run. The closer a patient is to the top of the match, the more they will have access to a higher-quality kidney.

Another member shared concerns about the candidate notification samples not being patient-friendly because the reading level is too high. She explained that some programs cannot use the samples and are spending additional time rewriting them. The member also shared concerns about the policy implementation being one year. She stated that one year is too long for Black and African-American candidates to wait for programs to assess their waiting lists.

Staff inquired about additional efforts to help programs. A member replied that the OPTN could consider evaluating the questions programs have been asking and providing them with the appropriate support so they don't feel overburdened. Another member noted a lack of understanding of the policy from patients. He shared that staff would call some of the patients at their program to help them understand this policy's importance. Another member agreed and added that the purpose of the

candidate notifications are to notify patients of this policy with the hope that they would be able to self-advocate, but this has resulted in a missed opportunity because patients don't understand the complexity of the proposal and therefore can't effectively advocate for something they don't understand.

Next steps:

The Committee will hear a six-month monitoring report on *Modify Waiting Time for Candidates Affected by Race-Inclusive eGFR Calculations*.

2. Ethical Analysis of Normothermic Regional Perfusion, OPTN Ethics Committee

Decision #2: There were no decisions made by the Committee.

The Committee heard a public comment presentation titled *Ethical Analysis of Normothermic Regional Perfusion (NRP)* from the Ethics Committee. The purpose of the white paper is to examine the ethical implications of NRP according to the ethical principles of nonmaleficence, respect for persons, and utility. The Ethics Committee is seeking feedback on the following:

- What information should be disclosed to potential donors and next of kin regarding NRP, and how should one approach disclosure?
- Are there any ethical arguments or additional evidence that haven't been presented that should be considered in the analysis?

Summary of discussion:

Regarding donor management, a member noted that it's shocking that there is no guidance on how the treatment team should manage the patient. He commented that a patient-proclaimed brain dead usually has an organ procurement organization (OPO) involved in management and receives guidance from the accepting team. However, he shared that the accepting team has no direct input from management in their program. He further shared that when the patients arrive at the hospital, withdrawal care is often done either in the post-anesthesia care unit (PACU) or the operating room (OR), and the accepting team is not in the room and does not guide management leading up to that point. He further commented that patients do not always have a smooth withdrawal of care compared to patients who are not donors, such as using medications to help alleviate air hunger. The member explained that the goal is to ensure the patient is comfortable and not increase the speed of the dying process. A member suggested that the Ethics Committee consider addressing withdrawal issues that may come up and the management of a potential donor. The presenter asked if the feedback applies to NRP or donor after cardiac death (DCD) donors. The member replied that feedback is for anyone considered DCD because it's before they become a donor.

A member asked if the family must consent to doing NRP versus traditional DCD donation. The presenter replied that they reviewed many protocols and determined that some centers do while others do not, and there's no standard experience. Members agreed that there should be some standardization around consenting to NRP. A member encouraged that NRP disclosure should be very clear, as this information is difficult to understand. She explained that if there is a misinterpretation of what NRP is, and donor families don't understand, that could impact recipients and the expansion of the donor pool.

A member noted that it's essential to have public support because the public could negatively perceive NRP. He inquired if there was a legal representation included in this project. The presenter replied that

the Ethics Committee is mindful of public perception and that there was legal representation from the workgroup.

Next steps:

The Committee will submit feedback on the Ethics proposal to be posted to the OPTN.

3. Workgroup Update: Refit KDPI without Race and HCV

Decision #3: There were no decisions made by the Committee.

The Committee heard a workgroup update on Refit KDPI without Race and Hepatitis C virus (HCV). This project aims to better reflect the quality and post-transplant survival of kidneys from deceased donors identifying as African American and HCV-positive.

Studies have shown that race should not be used in clinical decision-making as it is not an accurate proxy for genetic differences. Additionally, HCV treatment was less available in 2009 than it is now. HCV Nucleic Acid Amplification Testing (NAAT) testing and antiviral treatment have become more readily available, and kidney recipients have excellent kidney function at 12 months post-transplant.

In addition to other variables, race and HCV variables in the Kidney Donor Profile Index (KDPI) calculation determine the kidney allocation sequence. When all variables in the KDPI calculation are the same between two deceased donors except for race, the differences in the race variable play a role in dictating the kidney allocation sequence. When kidneys go to different allocation sequences, it may influence the program's behavior in accepting or declining the kidney, which may result in a higher non-use rate of that organ.

The Committee submitted a Scientific Registry of Transplantation (SRTR) modeling request to refit the KDPI calculation without race and HCV variables. The KDPI modeling aims to provide the Workgroup with sufficient evidence to propose OPTN policy change.

Summary of discussion:

A member asked what the weight of the race and HCV variables are. The Chair replied that the workgroup considered two potential paths: zero out race and HCV or remove the variables and refit the KDPI calculation. Refitting the calculation will place more weight on quantifiable biological matters. Another member asked what would happen to the KDPI calculation if African American is selected for race and HCV-negative is selected. The Chair explained that those are two different variables that have their own weight and are calculated independently of each other. Another member asked if testing for APOL1 could be used. The Chair replied that studies for APOL1 testing are still underway.

Next steps:

The Committee will review the SRTR modeling request upon return and make a recommendation to the MAC.

4. Concepts for a Collaborative Approach to Living Donor Data Collection, OPTN Living Donor Committee

Decision #4: There were no decisions made by the Committee.

The Committee heard a public comment presentation titled *Concepts for a Collaborative Approach to Living Donor Data Collection* from the Living Donor Committee. The purpose of the concept paper is to

identify gaps in knowledge related to the long-term outcomes of living donors and barriers to living donation. The Living Donor Committee is seeking feedback on the following:

- Input from living donors
 - What are living donors' preferences on how to engage with long-term follow-up?
 - What data do potential living donors need to inform decision-making and post-donation healthcare?
- Input on definition/terminology
 - Is the living donor candidate the correct term? Is the proposed definition appropriate?
 - How do living donor programs define evaluation?
- Input on data collection
 - What is the minimum amount of data necessary to collect on living donor candidates?
 - What are the specific necessary data elements?
 - What recommendations do transplant coordinators have on updates to OPTN living donor data collection forms?
- Input on concepts
 - How do living donor programs recommend operationalizing data collection on living donor candidates and donation decisions to reduce the burden?

Summary of discussion:

The Chair commented that better data will help guide decisions regarding patient candidacy and would be helpful going forward. He noted that it was surprising to include collection of APOL1 risk as this data element as it is not commonly collected. The presenter replied that the idea of the concept paper is to consider how to operationalize the data collection and understand what kind of data will be responsible for collecting during this time. The Chair also asked if the project's purpose is to obtain more data on patients, what measures are in place to protect the data on those who have donated and those who have not. The presenter replied that the SRTR would be the entity responsible for collecting and storing this data. They have a high level of security regarding that data being confidential and protected.

5. New Project Brainstorm & Open Discussion

Decision #5: There were no decisions made by the Committee.

The Committee brainstormed new projects and had an open discussion.

Summary of discussion:

The Chair commented that the last couple of Committee projects have been kidney-focused, and he encouraged members to bring forth other issues that they are aware of with other organs as it relate to the charge of the Committee.

A member voiced concerns about the incarcerated patient population and shared that she had a patient who needed a heart transplant and eventually was put on a left ventricular assist device (LVAD). She highlighted that the incarcerated patient had no finances, was homeless, had no support, and therefore was denied a heart transplant. She inquired about resources for this specific population. A member asked what happens to a patient on the waiting list who becomes incarcerated. A member shared that he experienced a similar situation with a patient and explained that one of the unclear issues is that once a patient is incarcerated, they are not financially clear until they have authorization from the jailhouse system. He further explained that the organ allocation and transplant expenses no longer go to the patient's insurance; therefore, the patient became delisted. I.

Another member stated that the main limitation for the incarcerated population awaiting a transplant is their financial clearance, which would be a barrier to them being listed. He noted that this may be a more extensive discussion and outside of the scope of the OPTN. The Chair asked if a patient could remain an organ donor after becoming incarcerated. Another member replied yes, but they may face challenges.

A member commented that the Committee should consider focusing on projects that may expand the donor pool or utilization of organs. Another member expressed concerns about the geographical distribution of organ allocation. He explained that there is a concern among smaller centers that when the organs transition to a continuous distribution framework, larger centers will receive more organ offers than smaller centers.

6. WebEx Transition

Decision #6: There were no decisions made by the Committee.

Staff informed the Committee that monthly Committee meetings will transition from GoToMeeting to the Webex platform starting on September 18, 2023.

Summary of discussion:

There were no further discussions.

Upcoming Meeting

- September 18, 2023, at 3 pm ET

Attendance

- **Committee Members**
 - Adrian Lawrence
 - Alejandro Diez
 - Anthony Panos
 - April Stempien-Otero
 - Catherine Vasick
 - Christiana Gjelaj
 - Jason Narverud
 - Niviann Blondet
 - Oscar K. Serrano
 - Sandy Edwards
 - Steve Averhart
 - Tony Urey
- **HRSA Representatives**
 - Kala Rochelle
 - Shelley Grant
- **SRTR Staff**
 - Bryn Thompson
 - Monica Colvin
- **UNOS Staff**
 - Betsy Gans
 - Cole Fox
 - Darby Harris
 - Elena Liberatore
 - Jesse Howell
 - Kelley Poff
 - Krissy Laurie
 - Meghan McDermott
 - Lauren Mauk
 - Tamika Watkins
 - Tina Rhoades
- **Other Attendees**
 - Keren Ladin
 - Stevan Gonzalez
 - Valinda Jones (Visiting board member)