

**OPTN Minority Affairs Committee
Meeting Summary
December 18, 2023
Conference Call**

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

Introduction

The OPTN Minority Affairs Committee (the Committee) met via Webex teleconference on 12/18/2023 to discuss the following agenda items:

1. Public Access Plan
2. OPTN Board of Directors Debrief
3. OPTN Data Advisory Committee's Pre-Waitlist Data Collection Workgroup
4. MAC's Next Project

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

1. Public Access Plan

The Committee heard an overview of the public access plan, which will allow OPTN Committee meetings to be live-streamed and allow the public to address the Committee during an open forum.

Summary of discussion:

There were no further discussions.

2. OPTN Board of Directors Debrief

The Committee heard a debrief about the OPTN Board of Directors meeting that took place on December 4, 2023, in St. Louis, MI.

Summary of discussion:

There were no further discussions.

3. OPTN Data Advisory Committee's Pre-Waitlist Data Collection Workgroup

The Chair provided an update about the OPTN Data Advisory Committee's (DAC) new project on pre-waitlist data collection. The Chair shared that the Committee's previous project idea, *Data Collection to Assess Socioeconomic Status and Access to Transplant*, which focused on collecting data regarding transplant candidate socioeconomic status, may benefit DAC as they begin their new project and as it aligns with their scope.

Summary of discussion:

A member expressed that DAC project work is essential and shared that the transplant recipient registration form (TRR) forms are confusing and need more clarification.

4. MAC's Next Steps

The Committee continued their discussion regarding the Committee's next project idea. The Committee heard an overview of the following project ideas:

- Incarcerated population
 - The OPTN Ethics Committee has explored this population:
 - [Assessment for Transplant Candidacy](#) (2021)
 - [Convicted Criminals and Transplant Evaluation](#) (2015)
 - [Ethics of Organ Donation from Condemned Prisoners](#) (2014)
- Race-neutral OPTN policy
 - Requires all calculations/tests used for the purposes of the OPTN to be race-neutral.
 - OPTN Policy 9.5.B: *Requirements for Cystic Fibrosis MELD or PELD Score Exceptions*.
 - Candidates apply for/ receive MELD or PELD exception; the Forced Expiratory Volume (FEV1) test can involve race.

The Committee was asked how they would like to proceed with the race-neutral OPTN policy project.

Summary of discussion:

Decision #1: The Committee determined that additional membership feedback was needed to determine which project the MAC should move forward with.

Incarcerated population

A member asked if it is possible to collaborate with the OPTN Ethics Committee on project ideas since they have worked on various projects regarding the incarcerated population. Staff replied that the Committee could collaborate with the Ethics Committee; however, any new project related to the incarcerated population would need to be different from what the Ethics Committee has already explored and worked on. The member further inquired if the Ethics Committee has looked at any subpopulations in the incarcerated population, such as gender, ethnicity, or age. The Vice-Chair commented that it is helpful to understand the questions the Committee is interested in answering within this population.

Another member asked if there was data on incarcerated individuals who needed a transplant and was declined. The Chair responded that gathering data on individuals not registered on the waitlist may be challenging. Another member commented that incarcerated individuals may get dialysis through large dialysis organizations. Another member shared that their center had a patient who was incarcerated after receiving a transplant and that it was difficult to follow the patient post-transplant. She suggested looking into any available information about recipients who are incarcerated.

The Chair agreed and commented that there are many questions the Committee can investigate, such as what happens to the wait time of individuals who are registered on the waitlist and are incarcerated. Another member suggested looking at data on the total number of people incarcerated in the U.S. and then further breaking down data based on age, sex, race, etc., which may help predict the rate of End-Stage Renal Disease (ESRD) in the prison population. Staff clarified that the OPTN does not collect information on incarcerated individuals.

There was consensus amongst members that the Committee would like to review data on the incarcerated population.

Race-neutral OPTN Policy

A member noted that it's essential to consider what framework should be used to determine if an equation should be race-neutral, as previous and new tests are available. Another member noted that the American Thoracic Society published an article on Race, Ethnicity, and Pulmonary Function Tests in which they denounced the use of race-inclusive calculations. The Vice-Chair stated that an advantage of addressing the race-neutral OPTN policy first is that the Committee has experience and background working on race-neutral projects, whereas the incarcerated population project may include additional work upfront to collect data.

The Committee was asked which project idea they would like to move forward with.

- Incarcerated population: 3 members support this project idea.
- Race-neutral OPTN policy: 6 members support this project idea.

The Committee determined that more membership feedback was needed to decide which project the MAC should proceed with.

Next steps:

The Committee determined that more information on the availability of incarcerated population data and additional membership feedback was needed to decide which project the MAC should move forward with.

Upcoming Meeting

- January 22, 2024 at 3 pm ET

Attendance

- **Committee Members**
 - Alejandro Diez
 - Oscar Serrano
 - Catherine Vascik
 - Tony Urey
 - Tatia Jackson
 - Jason Narverud
 - Sandra Edwards
 - April Stempien-Otero
 - Amaka Eneanya
 - Obi Ekwenna
 - Adrian Lawrence
- **HRSA Representatives**
 - Marilyn Levi
 - Mesmin Germain
 - Jim Bowman
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Kelley Poff
 - Tamika Watkins
 - Kaitlin Swanner
 - Houlder Hudgins
 - Jesse Howell
 - Betsy Gans