

# **Meeting Summary**

# OPTN Minority Affairs Committee Meeting Summary May 19, 2025 Conference Call

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

## Introduction

The OPTN Minority Affairs Committee (the Committee) met via WebEx teleconference on 05/19/2025 to discuss the following agenda items:

- 1. Recap of Proposal and Post- Public Comment Recommendations
- 2. Discuss educational resources for Monitor Ongoing eGFR Modification Policy Requirements

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

## 1. Recap of Proposal and Post- Public Comment Recommendations

The Committee reviewed the *Monitor Ongoing eGFR Modification Policy Requirements* public comment proposal and post public comment recommendations made by the Committee on March 31, 2025.

Post public- comment recommendations included:

- Retain retroactive notification requirement and provide transplant programs with a one-year timeframe for completion.
- Establish a 10- business day timeframe for notifying candidates following a program's receipt of the eGFR modification submission outcome from the OPTN.

#### Summary of discussion:

No decisions were made.

There was no discussion.

#### Next steps:

The Committee discussed educational resources to support the implementation of this proposal.

#### 2. Discuss educational resources for Monitor Ongoing eGFR Modification Policy Requirements

The Committee provided feedback to help inform the development of useful and educational resources. These resources aim to provide transplant programs with the tools they need to successfully implement the ongoing and updated requirements of *OPTN Policy 3.7.D: Waiting Time Modifications for Kidney Candidates Affected by Race-Inclusive eGFR Calculations*.

Resources discussed by the Committee included:

- Education for patients
- Process document
- Protocol checklist

Summary of discussion:

No decisions were made.

When discussing accessibility of patient resources, a member emphasized the importance of using simplified, patient-friendly language, noting that many patients struggle with medical terminology and technical content. A patient representative on the Committee echoed this sentiment, expressing that patients often feel overwhelmed by the volume and complexity of information they receive. This member urged that materials be written at an accessible reading level and free of jargon and abbreviations. They suggested that educational materials for patients include patient stories or testimonials, as personal narratives can make the content more engaging, digestible and less abstract.

The Committee then discussed delivery of patient resources. Members highlighted that that patients differ widely in how they consume information. Some patients prefer printed or physical materials such as brochures, while others prefer to access digital platforms to access information. A member emphasized the importance of updating the patient brochure in the eGFR Toolkit on the OPTN Website and asked if it could be required for patients to receive a copy upon registration. The Committee discussed that while providing education to patients is essential, transplant programs should be able to tailor education and its delivery their own patient populations. Members agreed that the OPTN should avoid being overly prescriptive, and instead offer a flexible framework with optional tools that programs can adapt as needed.

Towards the end of the meeting, the Committee provided feedback on the draft process document and draft protocol checklist. Transplant coordinator representatives expressed positive feedback on the tools, noting that they were well-organized, thorough, and useful, particularly for programs seeking structured guidance or onboarding new staff. Multiple members appreciated the clarity and practicality of the tools, particularly considering requests from the transplant community for "how-to" guidance. The Committee agreed that these tools should offer a helpful structure but allow customization to fit individual program workflows. Several members agreed that their respective programs use similar checklists and appreciated the tool's alignment with that practice.

#### Next steps:

The OPTN will use the Committee's feedback to continue developing educational resources.

#### **Upcoming Meetings**

• June 16, 2025, 3-4pm ET

## Attendance

# • Committee Members

- o Alejandro Diez
- o Oscar K. Serrano
- o Adrian Lawrence
- o Catherine Vascik
- o Hilda Fernandez
- o Anthony Panos
- o Donna Dennis
- o John Bayton
- o Christy Baune
- o Ruben E Quiros Tejeira
- o Obi Davies Ekwenna
- o April Stempien-Otero
- o Tony (Marcus) Urey
- SRTR Staff
  - o Warren McKinney
  - o Bryn Thompson
  - o Monica Colvin
- UNOS Staff
  - o Betsy Gans
  - o Houlder Hudgins
  - o Susan Tlusty
  - o Kelley Poff
- Other Attendees
  - o Rexanah P. Wyse Morrissette