OPTN Minority Affairs Committee
Meeting Summary
August 19, 2024
Conference Call

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

Introduction

The OPTN Minority Affairs Committee (the Committee) met via Webex teleconference on 08/19/24 to discuss the following agenda items:

1. July 15th meeting recap
2. Protocol steps and documentation

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

1. July 15th meeting recap

The Committee heard a summary of progress from their last meeting.

- The Committee supported the inclusion of the following protocol steps for *3.7.D.i Notification Requirement*
    o Process for confirming candidate race
    o Process for notifying candidates twice to 1) Inform candidates of the policy before or upon candidate registration and 2) to inform candidates of their eligibility
    o Process for notifying/asking for supporting documentation from dialysis units (when applicable)

- The Committee supported the inclusion of the following protocol steps for *3.7.D.ii Determination of Eligible Candidates*

    o Listing of available internal and external sources for seeking supporting documentation
    o Process for recording if documentation was or was not found for each candidate

Summary of discussion:

No decisions were made.

2. Protocol steps and documentation

The Committee continued to discuss a protocol for ongoing eGFR monitoring requirements.

The Committee reviewed the parts of ongoing eGFR policy requirements.
1. Continue to send a notification to all newly registered kidney candidates to make them aware of the policy
2. Assess newly registered kidney candidates to determine eligibility
3. Submit completed waiting time modification requests to the OPTN for every candidate who should have qualified to accrue waiting time sooner

For each part of the ongoing requirements, the Committee considered the following questions:

- Should any changes be proposed to current ongoing policy requirements?
  - Clarity/overall improvements
- Should ongoing policy requirements be included in protocol?
  - Should details or sub-steps be included?
- Should ongoing requirements be verified with documentation?
  - Should the program be required to provide documentation supporting this portion of the protocol?

Summary of discussion:

3.7.D.i Notification Requirement

- Language surrounding notifications should be clearer and more distinct
  - Notification one: waiting time modification education notification (education notification)
  - Notification two: waiting time modification outcome notification (outcome notification)
- Strike previous recommendation for *Process for notifying/asking for supporting documentation from dialysis units (when applicable)*

3.7.D.ii Determination of Eligible Candidates

- Policy language should indicate that candidates accruing waiting time with dialysis criteria are included in the scope of eligibility
- Inclusion of a protocol step that requires the program being surveyed to describe their process for reviewing all applicable laboratory data from listed internal and external sources

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3.7.D.i Notification Requirement

When discussing ongoing requirements for *3.7.D.i Notification Requirement*, members suggested that the policy should be clearer about when the second notification is required. Members expressed that the word "eligible" could be interpreted in different ways. For example, any candidate that is registered as Black or African American could be seen as eligible, but the Committee supports that the second notification should be made to a candidate after it is known whether they received a waiting time modification. For this reason, the Committee supports language that specifies notification two as the waiting time modification outcome notification. Another member added that specifying notification one as the waiting time modification education notification would help to distinguish one notification from the other. Members agreed, but another member reminded the Committee that both notification requirements may be fulfilled at the same time or on separate occasions based on the candidate's race and availability of supporting documentation. A member clarified that notification requirements could be fulfilled during the candidate evaluation process with face-to-face conversations. They suggested that implementation materials should highlight this, as the use of notification letters may no longer be the most practical means of communicating with candidates. A patient representative suggested a more streamlined approach for notifying candidates, such as requiring all hospitals to use the same notification method.

In previous conversations, the Committee supported the inclusion of a process for notifying/asking for supporting documentation from dialysis units (when applicable) in the ongoing eGFR monitoring protocol. During this meeting, they determined that a requirement to notify dialysis centers was

unnecessary, as this could cause additional administrative burden. Additionally, they noted that listing specific places to seek supporting documentation would be better suited in a program's standard operating procedure (SOP) or a Frequently Asked Questions (FAQs) resource developed by the OPTN.

3.7.D.ii Determination of Eligible Candidates

The Committee then turned their attention to ongoing requirements for *3.7.D.ii Determination of Eligible Candidates.* The Committee supported the inclusion of policy language to specify that candidates accruing waiting time with dialysis criteria are included in the scope of eligibility, as this was a point of confusion during the January 2023 implementation. In addition to listing available internal and external sources for seeking supporting documentation, the Committee also supported the inclusion of a step that requires the program being surveyed to describe their process for reviewing all applicable laboratory data from listed internal and external sources. When asked if any additional protocol steps should be recommended for *3.7.D.ii Determination of Eligible Candidates,* members stated that their recommendations to date are adequate and cautioned against additional protocol requirements that would make the policy too prescriptive or burdensome.

3.7.D.iii Application for Waiting Time Modification

When asked about the addition of protocol steps for the *3.7.D.iii Application for Waiting Time Modification* portion of the policy, members expressed that they are not necessary. The Committee explained that this part of the policy requires submission of documentation to the OPTN, so a paper trail for these submissions already exists.

<u>Next steps:</u>

The Committee will continue these discussions during their next meeting.

Upcoming Meetings
- September 16, 2024- 3-4pm ET (Teleconference)
- September 30, 2024- Detroit, MI (In Person)

Attendance

- **Committee Members**
  - Oscar Serrano
  - Adrian Lawrence
  - Anthony Panos
  - Catherine Vascik
  - Christy Baune
  - Donna Dennis
  - Hilda Fernandez
  - Ruben Quiros- Tejeira
  - Sandy Edwards
  - Obi Davies Ekwenna
  - Steve Averhart
- **HRSA Representatives**
  - Shelley Tims Grants
- **SRTR Staff**
  - Bryn Thompson
  - Monica Colvin
- **UNOS Staff**
  - Alex Carmack
  - Kelley Poff
  - Laura Schmitt
  - Meng Li
- **Other Attendees**
  - Ashley Cardinas
  - Kristen Smith
  - Rachel White
  - Karl Neuman