

**OPTN Patient Affairs Committee  
Meeting Summary  
November 14, 2023  
Conference Call**

**Garrett Erdle, MBA, Chair  
Molly McCarthy, Vice Chair**

## **Introduction**

The OPTN Patient Affairs Committee (PAC), the Committee, met via WebEx teleconference on 11/14/2023 to discuss the following agenda items:

1. Welcome and Announcements
2. Inactive Status and Disparate Impact on Access to Kidney Transplantation by Race
3. Inactive Status Data Request
4. Patient Health Communication

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

### **1. Welcome and Announcements**

The vice chair of the Committee provided the group with updates regarding upcoming vice chair nominations.

#### Presentation summary:

- October: Five current or former members expressed interest in the Vice Chair position
  - Candidates received information about next steps in the process on November 9
- November: PAC member survey to select top four candidates due November 16
  - Survey includes candidate name, OPTN committee history, and personal statement
  - Members must select four candidates to complete the survey
- December: Leadership and support staff hold interviews with top four candidates on December 7
- January: Two finalists will be submitted to OPTN Vice President, Dr. Rich Formica, for final appointment

#### Summary of discussion:

**The Committee did not have any further discussion regarding this agenda item.**

### **2. Inactive Status and Disparate Impact on Access to Kidney Transplantation by Race**

The Committee heard a presentation on how inactive status has impacted access to kidney transplantation.

#### Presentation summary:

- Transplant rates include inactive and active patients
  - Only active patients can receive deceased donor organ offers
- Inactive status is independently associated with mortality [Grams et al. *AJT* 2013;13(4):1012]

- Based on OPTN Waiting List representation, Black and Hispanic populations have a higher percentage of people that experience an inactive status change
- Those who are White have a 35% increased chance of becoming active once they are made inactive
- White individuals have a 24% higher chance to becoming active versus Hispanic individuals
- Subgroups of highly sensitized patients (80-100% CPRA) continue to experience disparities as it relates to access to transplantation
- The probability of a Hispanic individual becoming active after being made inactive due to incomplete workup is statistically significantly lower than Black or White individuals

Conclusions:

- There continue to be access issues for minority groups who experience inactive status to a greater extent than whites
  - Lower chances of resolving issues of inactivity in patients whose CPRA>80%
- Hispanic patients have a statistically lower chance of resolving potentially modifiable reasons for inactivity
  - Incomplete work-up
  - Insurance issues
- Investigate if activity status may be suitable as a marker for health access
- Who ultimately is responsible for addressing issues of inactivity?

Summary of discussion:

**The Committee did not make any decisions; however, they did have a discussion around inactive status and disparities.**

A member highlighted the challenges faced by Hispanic communities, including language barriers and lack of awareness about medical procedures like transplants. She shared her personal experience as a white woman navigating the transplant referral process, underscoring the need for improved communication from transplant centers to ensure that patients comprehend the procedures and information necessary for their healthcare.

The presenter noted that there is a higher mortality rate for inactive individuals, citing incomplete workups as a common reason for inactivity. The Vice Chair acknowledged the significance of the topic and mentioned the strong interest from the group, highlighting the importance of exploring what happens to patients in inactive status and the need for clarity on how to transition back to active status.

### 3. Inactive Status Data Request

A member of the Committee provided the group with a brief review of the data request that OPTN contractor staff have been working on with members of the Committee.

Presentation summary:

Data Request:

- Data Points:
  - Count and percent of candidates waiting active vs inactive past 10 years
  - Median days waiting at inactive status for candidates ever waiting, past 10 years
  - Medians days active before inactive, past 10 years

- Rate of active status change (either active to inactive or inactive to active), per year for past 10 years
- Stratified:
  - By organ
  - Race/ethnicity
  - Sex at birth
  - State of residence at listing
  - Level of education

Summary of discussion:

**Decision #1: The Committee decided to move forward with the formal data request and agreed that the proposed metrics were adequate.**

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A member acknowledged the complexity of providing multi-listing data segmented by the number of registrations per patient. Other members responded, noting that delving into various levels of detail regarding multi-listing would necessitate considerable additional time. As a result, for the time being, they will rely on total registration data to provide a general overview without delving into individual patient-level specifics. However, it was emphasized that data indicating whether candidates were multi-listed can be extracted and will be included in the initial data request.

In addition to the multi-listing information, it was confirmed that all other data points previously reviewed will be incorporated in the initial data request, except for the estimated glomerular filtration rate (eGFR) information, which may require additional time to acquire.

Next steps:

OPTN contractor staff will make a formal data request to the Research Department.

**4. Patient Health Communication**

The Committee continued a previous conversation around patient health communication.

Presentation summary:

Review:

- A recent survey showed communication approval rating (222 transplant recipients):
  - 83% pre-pandemic
  - 57% post-pandemic
- Discussed what information you did not receive and identified gaps
- Inconsistent information within medical systems
- Limited information comes out of transplant centers
- Health and safety information did not specify guidance for the immunocompromised
  - Transplant Centers were not the preferred source for this information
- Available treatments were not widely known

Summary of discussion:

**The Committee did not make any decisions regarding this agenda item; however, they did discuss potential solutions for effective patient-communication strategies.**

The presenting Committee member proposed a solution to address the breakdown in communication between transplant centers and recipients. The suggested solution involved acquiring and disseminating medical information to recipients, with a particular focus on infectious disease-related data. The member recommended promptly communicating relevant information to recipients, which could be gathered by interns, residents, or students. In cases where a transplant center lacked designated personnel for information collection, hiring a medical professional was advised. Once obtained, the information could be disseminated through portals, newsletters, or personal interactions.

The Committee acknowledged the challenge of varying information among transplant centers but still discussed the possibility of drafting a policy outlining communication standards such as the level of rigor and frequency of pertinent infectious disease information. The discussion raised concerns about utilizing prescriptive policies. Considering that medical information is constantly evolving, the policy would also need to be adjusted. A member emphasized the benefit of drafting a policy, highlighting that while transplant centers may have different information, adherence to standards set by organizations like the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH) offer definitive guidance.

A member expressed the belief that primary care doctors should share an equal responsibility with transplant doctors in disseminating infectious disease information. She shared her experience, noting that her transplant doctors primarily focus on the organ and often defer other matters to her primary care provider. In response, a committee member asserted that this shouldn't be the norm, emphasizing that transplant centers typically have an infectious disease doctor who can offer the necessary information and expertise directly to recipients.

A member contended that, from his perspective, the matter at hand is not solely a transplant issue but rather an immunity issue. He argued that the Committee's scope encompasses areas under the immunity umbrella such as cancer. If the provided guidance is not applicable to all categories under the immunity umbrella, it may result in inconsistent guidance. Expressing concern about the coherence of the guidance, he suggested that the Committee should forward it to the Board. The Board, in turn, could relay it to a higher entity better equipped to institute the specified guidance. In response, another member asserted that this is unequivocally a transplant issue. He maintained that as an organization focused on transplantation, the OPTN must take the lead in resolving this specific issue related to transplants.

A member highlighted that the American Society of Transplantation (AST) gathers immunity-related data concerning transplantation. The AST provided specific information on dealing with Covid, prompting the member to question whether the OPTN and transplant centers could utilize AST to source their medical information. In response, another member acknowledged that incorporating this into policy might pose challenges due to its unprecedented nature. He emphasized the complexity of individual patient nuances, suggesting that patients may not find answers pertinent to their specific situations on the AST site. The member argued that even if recipients possess this information, their doctors may not discuss their circumstances with them, diminishing the AST site's value for recipients in such cases.

The member who raised the question agreed with the sentiment expressed but maintained that establishing a designated repository of data, such as the AST, accessible to all transplant centers, would be beneficial. This, in their view, could serve as a foundational step towards addressing how to

effectively communicate this information to recipients. However, another member expressed reservations about information becoming overly generalized, particularly for patients with unique or specific concerns, potentially leading to misinformation. She further asserted that the responsibility for improved communication should primarily rest with the transplant center rather than the OPTN.

In response, a Committee member clarified that this issue falls within the purview of the OPTN, emphasizing the organization's direct involvement in transplant areas and organ protection. He asserted that if transplant centers are unwilling to engage with patients on infectious disease matters, the OPTN must take proactive measures to address the communication gap.

Additionally, a member proposed that the Committee consider initiating a pilot program involving one to two transplant centers along with the participation of the patient's general practitioner. The aim of this pilot program would be for the OPTN and transplant centers to collaboratively assess the feasibility within their operations and establish a foundational structure for improving communication in the future. While the group is collectively aligned in recognizing the need for action, there is not yet a consensus on the approach to addressing and resolving the issues identified in infectious disease-related communication between transplant centers and recipients.

Next steps:

OPTN contractor staff will take the suggestions from today's meeting to determine what the next steps in this potential project might be.

**Upcoming Meeting(s)**

- December 12, 2023

## Attendance

- **Committee Members**
  - Molly McCarthy
  - Denise Abbey
  - Tonya Gomez
  - Lorrinda Gray-Davis
  - Calvin Henry
  - Sanjay Kulkarni
  - Wendy Leavitt
  - Andreas Price
  - Cathy Ramage
  - Kristen Ramsay
  - Julie Spear
  - John Sperzel
  - Steve Weitzen
  - Justin Wilkerson
- **HRSA Representatives**
  - Jim Bowman
  - Mesmin Germain
- **SRTR Staff**
  - Katie Audette
- **UNOS Staff**
  - Alex Carmack
  - Kaitlin Swanner
  - Kim Uccellini
  - Roger Brown
  - Houlder Hudgins
  - Desiree Tenenbaum