

**OPTN Patient Affairs Committee
Meeting Summary
November 19, 2024
Teleconference**

**Molly McCarthy, Chair
Lorrinda Gray Davis, Vice Chair**

Introduction

The OPTN Patient Affairs Committee (the Committee) met via WebEx teleconference on 11/19/2024 to discuss the following agenda items:

1. Welcome and Announcements
2. SRTR Data Presentation: *Dynamics of inactive status use in adult kidney candidates by social determinants of health*

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

1. Welcome and Announcements

A new Committee Liaison from the OPTN contractor was introduced. An upcoming meeting of the OPTN Data Advisory Committee (DAC) was announced. DAC has asked for a representative from the OPTN Patient Affairs Committee to attend. Those interested in attending the DAC meeting were encouraged to reach out to the Committee Liaison.

Summary of discussion:

No decisions were made by the Committee.

There was no discussion on this agenda item.

2. SRTR Data Presentation: *Dynamics of inactive status use in adult kidney candidates by social determinants of health*

Representatives from the Scientific Registry of Transplant Recipients (SRTR) presented their findings on data requested by the Committee.

Data summary (as applicable):

SRTR staff conducted an analysis examining disparities in inactive status for adult kidney transplant candidates across two time periods: 2017-2019 and 2021-2023. The study focused on social determinants of health and investigated how different patient characteristics influence the timing and frequency of inactivation on the kidney transplant waiting list.

Key findings revealed statistically significant variations in inactive status usage across regions, with the Pacific Northwest (OPTN Region 6) showing the most notable differences. Patients were more likely to be inactivated if they were on Medicaid, older, or had a higher Body Mass Index (BMI). Notably, white non-Latino patients generally spent less time inactive compared to non-white or Latino patients.

The research examined three phases of the candidate journey: initial time to inactivation, time to activation after being listed inactive, and overall inactive status duration. In the recent period (2021-

2023), approximately 35.5% of patients were inactivated on their listing date, compared to 24% in the earlier period. The primary reasons for inactivation were incomplete workup and being temporarily too sick for transplant. The data also showed that patients remained inactive for five to six months while the candidate and center completed the workup.

The study employed multivariable adjusted models to control for various patient characteristics, allowing for a more nuanced understanding of inactivation patterns. While some statistically significant differences were observed across patient subgroups, the presenter emphasized that many of these differences may not be clinically significant on an absolute scale.

Representatives from the SRTR were unable to finish the presentation due to time constraints.

Summary of discussion:

The Committee made the decision to schedule an additional meeting in December to allow SRTR to complete this presentation and provide an opportunity for a more robust discussion by the Committee.

A Committee member asked if the researchers were able to differentiate between transplant centers that have a policy to communicate to their patients about inactive status. Representatives from the SRTR said that this center-specific data is not available. Another Committee member pointed out that distance to transplant centers could be a critical factor affecting patient activation, highlighting potential geographical barriers to transplant access.

An SRTR representative provided additional context about kidney transplant practices, noting that centers often list patients inactive before dialysis to accrue wait time, and this practice continues across regions. The Committee and presenters discussed that establishing a universal policy around this type of communication could provide more standardization across regions.

The Chair asked how the data has been shared within the OPTN. Committee support staff shared that the report was shared with everyone who supports the Committee, and the Committee can take this information and move it forward into a policy proposal or share it in other ways.

The Chair asked if best practices could be shared from centers that move candidates from inactive to active status more quickly. SRTR and committee support staff noted that the OPTN Membership and Professional Standards Committee previously considered a metric around inactive status as part of the transplant program performance metrics but decided not to pursue it since it could encourage transplant programs to remove candidates from the waiting list who are not likely to return to active status. SRTR staff recommended looking at waiting list status data in the context of transplant rates to assess how well a center does in getting candidates to transplant.

Committee members expressed support for an OPTN policy to mandate that centers notify candidates when they are inactive. Committee support staff noted that this Committee could bring that forward to the OPTN Policy Oversight Committee as a project, or the Committee could request that another committee take it on, like the OPTN Transplant Administrators Committee or Transplant Coordinators Committee. Members noted that the Executive Committee recently passed a resolution in support of the concept of the Committee's Patient Awareness and Listing Status project and found that it was most appropriate as a policy proposal with an application component.

Multiple Committee members thanked the SRTR for the presentation as discussed how it could be used as a potential pathway to improving transplant processes. They discussed the need for further

investigation into the underlying drivers of regional disparities and potential policy interventions. The Committee agreed to schedule a follow-up meeting to dig deeper into the data.

Next steps:

Contractor staff agreed to follow up with Committee members to determine a second date to allow SRTR representatives to complete their presentation, and allow for a more robust discussion by the Committee.

Upcoming Meetings

- December 4, 2024
- December 17, 2024

Attendance

- **Committee Members**
 - Molly McCarthy
 - Lorrinda Gray-Davis
 - Justin Wilkerson
 - Cody Reynolds
 - Patrice Ball
 - Andreas Price
 - Calvin Henry
 - Liz Devivo
 - Tonya Gomez
 - Karlett Parra
 - Michael Slipowitz
 - Michael Brown
 - Cathy Ramage
 - Steven Weitzen
- **HRSA Representatives**
 - Robert Johnson
- **SRTR Staff**
 - Grace Lyden
 - Allyson Hart
 - Katie Audette
 - Earnest Davis
- **UNOS Staff**
 - Alex Carmack
 - Kaitlin Swanner
 - Desiree Tenenbaum
 - Kimberly Uccellini
 - Jesse Howell
 - Houlder Hudgins