OPTN Patient Affairs Committee
Meeting Summary
December 4, 2024
Teleconference

Molly McCarthy, Chair
Lorrinda Gray Davis, Vice Chair

Introduction

The OPTN Patient Affairs Committee (the Committee) met via WebEx teleconference on 12/04/2024 to discuss the following agenda item:

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

A representative from SRTR presented on their report *Dynamics of inactive status use in adult kidney candidates by social determinants of health*. This presentation was a continuation from the previous meeting of the Committee. Following the presentation, the Committee discussed the findings in the report.

Presentation summary:

The analysis examined three key phases of the candidate journey. First, it looked at how long it takes candidates to be inactivated for the first time after listing. While statistical differences were found across various demographic factors (age, insurance status, BMI, race/ethnicity, and dialysis time), the presenter noted that these differences may not be clinically significant, as the differences typically around five percentage points. However, regional variations were more substantial, ranging from 65% to 90% probability of inactivation within the first five years after listing.

The second phase examined how long it takes candidates who start in inactive status to achieve active status for the first time. The median time to activation was generally between five to seven months across most groups, with Medicaid patients notably taking around nine months. Comparing 2017-2019 data to 2021-2023 data showed that racial and ethnic disparities in activation time have decreased, though regional variation remained, ranging from three months to over one year.

The final phase analyzed reactivation times for candidates made inactive at any point. In both study periods (2017-2019 and 2021-2023), about 62-65% of inactive candidates were reactivated within one year, while approximately 11% died or became too sick for transplant while inactive. The analysis revealed statistically significant differences in reactivation times across racial and ethnic groups, with white non-Latino candidates averaging six months to reactivation compared to ten months for Pacific Islander non-Latino candidates. Insurance type also showed notable differences, with privately insured patients taking about five months compared to eight months for Medicaid patients. Regional variations were substantial, with some regions showing median reactivation times of over one year, while Region 8 had the shortest median time to activation at about four months. The time spent on the waiting list also

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influenced reactivation times, with candidates inactivated during their first year experiencing shorter inactive periods compared to those inactivated later in their waiting time.

Summary of discussion:

No formal decisions were made by the Committee.

A Committee member shared their personal experience with inactivity due to the transplant center overlooking a test result that had been submitted, and lack of communication from the transplant center on that issue. The member questioned whether there is any way to track which transplant centers choose not to communicate status changes to their patients. A representative from SRTR acknowledged this is a limitation of existing OPTN and SRTR data as it does not capture detailed information about center-patient communication.

Another Committee member repeated these concerns, emphasizing the lack of standardization in communication practices across different transplant centers. They suggested that collecting more detailed codes about the reasons for inactivity and aligning the number of steps required for listing could improve transparency and patient understanding.

An SRTR representative cautioned against oversimplifying the issue of standardization, noting that the complexity and individuality of each patient's case makes it difficult to establish universal listing criteria. For example, some patients may need additional testing based on their medical history. They suggested that transplant programs may resist publishing their specific criteria due to the need for individualized assessment. Another member of the Committee supported this view, emphasizing the potential resistance from transplant programs towards any form of universal policy.

An SRTR representative suggested improving communication with patients, ensuring they understand their status, required steps, and the roles of both the patient and the center in the process. They believed that enhancing communication is a crucial area for improvement across transplant centers.

A member of the Committee emphasized the urgency of addressing the issue of inactivity, suggesting the Committee should focus on implementing practical solutions rather than waiting for perfect data or policies. They suggested that the Committee possesses sufficient expertise to pursue policies aimed at standardizing communication practices.

A representative from SRTR supported the idea of pursuing policy changes to address the variability in communication. They encouraged the Committee to leverage their expertise and patient feedback to push for standardization, even in the absence of comprehensive data on communication practices.

A Committee member suggested creating a clear "map" or checklist outlining the expected steps in the transplant process. They believed that such a roadmap could empower patients and caregivers by providing a better understanding of the process and their role in it.

Another Committee member asked about the potential for sharing the data analysis with other stakeholders within OPTN to encourage broader action. OPTN contractor staff noted that these data could be shared in a public comment proposal or potentially via other means as recommended by the committee. The Committee member also asked about the feasibility of identifying best practices from centers that demonstrate faster transitions from inactive to active status, recognizing that quicker activation might indicate a more effective approach.

A Committee member reiterated the original goal of the project: to ensure patients are informed about their inactive status. They proposed a policy mandating centers to notify all inactive candidates, stating that such a policy would be enforceable and subject to review.

A Committee member suggested sending the idea to the Patient Awareness of Listing Status Subcommittee (PALS), which is proposing a platform for patients to proactively track their status and understand the reasons for any delays. They suggested that implementing a multi-dimensional approach involving policy changes, technology solutions, and improved communication would be most effective in tackling waiting list inactivity.

OPTN contractor staff reminded the Committee that as a policy development committee, they may propose policies that address the identified problems. They reiterated the Executive Committee's recommendation to combine a policy mandating communication of inactive status with a technological solution for transparent status tracking, emphasizing the enforceability of such a policy.

Next steps:

The Committee will continue discussions on this topic and decide whether to pursue a project.

Upcoming Meetings

- December 17, 2024
- January 21, 2024

Attendance

- **Committee Members**
  - Molly McCarthy
  - Lorrinda Gray-Davis
  - Patrice Ball
  - Liz DeVivo
  - Michael Slipowitz
  - Michael Brown
  - Steve Weitzen
  - Cathy Ramage
- **SRTR Staff**
  - Grace Lyden
  - Allyson Hart
  - Katie Audette
  - Earnest Davis
- **UNOS Staff**
  - Alex Carmack
  - Kaitlin Swanner
  - Desiree Tenenbaum
  - Jesse Howell
  - Laura Schmitt