

**OPTN Patient Affairs Committee
Meeting Summary
May 21, 2024
Conference Call**

**Garrett W. Erdle, Chair
Molly J. McCarthy, Vice Chair**

Introduction

The Patient Affairs Committee met via WebEx teleconference on May 21, 2024, to discuss the following agenda items:

1. Welcome and Announcements
2. Require Notification for Inactive Status- Framing Out Project and Next Steps
3. Consider Inferential (SRTR) Data Request Related to Inactive Status
4. Public Forum

The following is a summary of the Committee’s May 21, 2024, discussion.

1. Welcome and Announcements

OPTN Contractor staff noted appreciation for comments on a Kidney Donor Profile Index (KDPI) educational video, confirming that these comments were submitted to the Expedious Task Force. A “save the date” for the September 10, 2024, meeting in Detroit was also sent via email to Committee members.

2. Require Notification for Inactive Status- Framing Out Project and Next Steps

No decisions were made.

OPTN Contractor staff presented a possible timeline and process for pursuing the inactive status notification project, including seeking feedback from other committees and taking the project proposal to the Policy Oversight Committee (POC) for approval in June. The Committee reviewed the project goals of patient empowerment and efficiency. The Committee reviewed two possible options for the project – a policy requirement allowing transplantation centers to decide the best notification system for their patients, or a contractor IT implementation of a notification system. The Committee reviewed several questions that are important to the development of the project, such as policy requirements and key metrics. Staff also mentioned possible internal collaborations with OPTN Contractor staff in Member Quality, Research, IT, and Enterprise Data Management. The Committee reviewed previous committee discussions on notification timing.

Summary of discussion:

A committee member said transplant centers do not communicate enough now and there must be a new platform for communicating status that is not left to the centers. Another member continued that both options should be implemented over time – centers should be required to communicate, and a new IT notification system should be implemented later. A member mentioned that hospitals give a variety of information at different times which can become confusing. A member suggested that status information could be put into a patient portal for simplicity.

Staff stated that OPTN policy requires written communication at time of listing and removal from waitlist (for reasons other than transplant) but there is not OPTN policy requiring other interim communications such as inactive status. The Committee discussed the importance of multiple avenues of communication about status and data on how often transplant centers contact their patients. Some members were supportive of a first step being the inclusion of this information in the patient portals that many hospitals already have in place for sharing lab results and appointment reminders, but concerns were shared that communication is not consistent across all transplant programs. A number of anecdotal examples of individuals not knowing that they were in inactive status were shared during the call. A Committee member shared her transplant program’s monthly process for reviewing inactive candidates, identifying what needs to happen to get the candidates to active status, and communicating to candidates why they are inactive and what they need to do.

Next Steps:

Staff will continue coordinating with the Committee and Committee leadership on the project plan.

3. Consider Inferential (SRTR) Data Request Related to Inactive Status

SRTR Contractor staff will be invited to outline the proposed data analysis on the June call.

Discussion Summary:

OPTN Contractor requested work group feedback on a developing SRTR data request to better understand potential disadvantaged populations related to inactive status. A Committee member noted that changes in the likelihood of inactive status over 10 years, demographic information related to inactive status, and differences/disparities in inactive reason codes were to be considered as part of the analysis.

SRTR staff stated that they are ready to submit the official data request when requested.

Next Steps:

SRTR will be invited to present an outline of the proposed data analysis to the full Committee before moving forward to finalize that data request.

4. Public Forum

Discussion Summary:

No public forum items were offered for discussion. The Committee requested an update on the status of the proposal *Establish Code of Conduct and Whistleblower Protection Bylaws*.¹ Staff shared that this proposal would be considered by the Board in June.

A Committee member shared that he had spoken with a potential Organ Procurement Organization CEO regarding an opportunity to speak at a future Committee meeting.

Some Committee members expressed a desire to move forward with the inactive status process. Staff reiterated that the Committee has all the information required to move the project forward to the Policy Oversight Committee for approval and reviewed potential timelines for developing a public comment proposal.

¹ OPTN, accessed June 14, 2024, <https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/establish-code-of-conduct-and-whistleblower-protection-bylaws>.

Upcoming Meetings

- June 18, 2024 conference call

May 21, 2024 Attendance

- **Committee Members**
 - Molly McCarthy
 - Lorrinda Gray-Davis
 - Densie Abbey
 - Cheri Coleman
 - Tonya Gomez
 - Calvin Henry
 - Wendy Leavitt
 - Andreas Price
 - Cathy Ramage
 - Julie Spear
 - John Sperzel
 - Steven Weitzen
 - Justin Wilkerson
- **HRSA Representatives**
 - Robert Johnson
- **UNOS Staff**
 - Shandie Covington
 - Houlder Hudgins
 - Kaitlin Swanner
 - Desiree Tenenbaum
 - Kimberly Uccellini
- **Other**
 - Michael Brown
 - Michael Slipowitz