OPTN ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK Meeting Summary

OPTN Patient Affairs Committee
Meeting Summary
May 20, 2025
Conference Call

Molly McCarthy, Chair
Lorrinda Gray Davis, Vice Chair

Introduction

The OPTN Patient Affairs Committee met via WebEx teleconference on 05/20/2025 to discuss the following agenda items:

1. Welcome and Announcements
2. Regrouping on Center Listing Criteria
3. Public Forum

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

1. Welcome and Announcements

The Chair welcomed the committee members and HRSA representatives. Contractor staff announced staffing changes. The Committee recognized and congratulated committee members who have been appointed to the OPTN Board of Directors.

2. Regrouping on Center Listing Criteria

HRSA staff facilitated a discussion on Center Listing Criteria

Summary of presentation:

HRSA staff introduced their new data analytics team, which has been established within the Division of Transplantation. The team is leading the pre-waitlist and ventilated patient data collection form efforts; both forms are undergoing the federal public comment review process. The pre-waitlist data effort will collect upstream data to better understand who is being referred, evaluated, and ultimately listed for transplant. On the recovery side, the data collection will focus on which potential donors are referred to organ procurement organizations (OPOs).

HRSA staff emphasized the importance of understanding the full patient journey, from referral to transplant, and that current data only allows analysis of patients from waitlist to transplant. HRSA staff aim to use the new data to identify barriers, such as variation in waitlist criteria across transplant programs, and to explore how this information can be made accessible and useful to patients and help more patients reach the waitlist. HRSA staff also intend to align with the Increasing Organ Transplant Access (IOTA) Model data requirements and coordinate their efforts with offices at Centers for Medicare and Medicaid Services (CMS). HRSA staff asked for Committee feedback on which aspects of the data are most useful and how this information can be communicated effectively to patients. HRSA staff provided the following references to information on the data collection efforts:

- Department of Health and Human Services data directive - OPTN
- One Page Letter for Administrator Signature (non grant support)

- Federal Register : Agency Information Collection Activities: Proposed Collection: Public Comment Request; Information Collection Request Title: Process Data for Organ Procurement and Transplantation Network

Summary of discussion:

Decision #1: The Committee agreed to review the six focus areas presented by HRSA staff and provide feedback to HRSA on prioritization.

The Vice Chair highlighted that many patients first learn about transplant after arriving at an emergency room or starting dialysis, and providing information and education earlier on would be beneficial. The Vice Chair also noted that sharing information and data about transplant with primary care providers and community health programs could help educate patients earlier in the process and improve access to transplant. HRSA staff noted that one goal of their data initiative is to close gaps across the transplant system by linking data collected by CMS and other sources throughout the patient journey. A member recommended including referring physicians in future discussions or working groups on this topic, given their critical role in helping patients access the most appropriate transplant program.

A member asked how HRSA would capture data on the pre-waitlist experience for patients that ultimately were not listed for transplant. HRSA staff noted the importance of acknowledging patients who do not make it to waitlist or transplant, and that while the initial focus of their efforts is to standardize data collection, they also intend to link disease prevalence data and end-stage organ failure data to obtain insights into this population and assess waitlist access.

Another member suggested transplant program information should include the program's benefits and potential risks to help patients make informed choices. The member commented the information could be considered like a prospectus, offering clear and balanced insights into each program. A HRSA staff member considered whether the OPTN should require a basic set of information that all transplant programs must provide to patients. HRSA staff asked for feedback on what that minimum standard should be and how to ensure the information is clear and accessible.

- A member proposed creating a standard list that programs would be required to share, including both positive information and known risks.
- Another member noted the importance of considerations for new transplant programs that may not have long-term outcome data, suggesting context should be provided to help patients understand those differences.
- The Chair supported creating a baseline level of required information, presented in a consistent format and multiple languages to help patients easily compare options.
- A member noted program criteria they considered fundamental information: if the program allows multi-organ listings, if they are willing to accept HIV-positive organs, if they accept other higher-risk organs, and whether they have living donor programs.
- SRTR contractor staff noted that some transplant program information is already available through SRTR's patient-accessible tools and asked whether the discussion focused on data not currently captured before waitlisting.
- HRSA staff acknowledged that relevant data currently exists across various platforms, including the OPTN and SRTR websites, but that it could be centralized and more accessible to help patients earlier in the process.

A HRSA staff member emphasized the importance of ensuring OPTN committees are answering the right questions for the community, and reiterated HRSA's goals to identify barriers that prevent patients from reaching the waitlist and improve transparency across the full patient journey. Committee members provided additional feedback on patient barriers and information needs.

- A Committee member raised a concern about patients losing time pursuing programs that may not be the best fit. They also questioned whether more information on program criteria could lead to overcrowding at highly preferred programs. HRSA suggested including both small and large programs in any pilot data efforts around program criteria, while monitoring potential capacity issues and unintended consequences.
- Committee members discussed the impact of insurance on patient choice and access. One member suggested including insurance compatibility (e.g., Medicaid vs. commercial plans) in transplant program information, with simple guidance to help patients navigate those barriers. The Chair agreed and noted that both geographic and insurance factors strongly influence where patients seek care.
- The Chair and Vice Chair highlighted that much of the transplant process is unfamiliar to patients and that early, accessible education is critical—especially for patients who are ill and overwhelmed. The Vice Chair shared examples where patients, once informed, pursued living donation, underscoring the importance of patient-centered communication in plain language.
- HRSA staff added that patients need to know what questions to ask and that information must be provided at appropriate points along their journey. HRSA staff stated their goal is to ensure patients receive the right information, at the right time, in a way that helps them better understand the transplant process.
- A member shared an example of a clerical error that led to their spouse being deactivated from the waitlist, raising concerns about how such events are tracked and reported. They asked whether patients are notified when errors occur and whether transplant programs are required to report them.
- HRSA staff acknowledged that every missed opportunity for transplant, whether it occurs because an organ is lost in transit or due to a mistaken inactivation, represents a lost chance to save a life. HRSA staff noted the importance of collecting data and understanding the frequency of these events and then presenting that information in a way that is clear and non-overwhelming for patients. HRSA staff noted at a minimum, there should be transparency for patients as to listing status, the types of organs they are eligible for, and whether offers have been declined on their behalf.

A HRSA staff member identified six areas of focus where they are seeking the Committee's participation and feedback:

1. Program waitlist criteria and whether IOTA requirements should be expanded to apply across the OPTN.
2. Using pre-waitlist data to understand why some patients don't reach the waitlist and whether they can be referred to another program more likely to list them.
3. Comparing transplant programs' stated criteria with their actual listing and transplant practices.
4. Improving transparency around organ offers.
5. Addressing active/inactive status transparency and identifying policy or technical solutions to improve it.
6. Exploring how patients are notified about adverse events and what information patients are seeking (ex: if they were bypassed for an organ offer due to non-compliance with policy or due to an external factor like a natural disaster).

The Chair expressed interest in supporting these efforts and proposed the Committee review these topics, assess any related work already underway or completed by the Committee, and provide feedback to HRSA on prioritization. HRSA staff reiterated their commitment to partnering with the Committee to ensure data reaches the patients and providers who need it most, and to support potential policy changes informed by this work. The Chair thanked HRSA for their engagement and reaffirmed the Committee's focus on projects that create meaningful, measurable impact for patients, donors, and caregivers.

Next steps:

HRSA will provide the Committee with follow-up materials, including a more detailed narrative of the six areas in which HRSA staff are seeking Committee feedback.

3. Public Forum

There were no comments or speakers for public forum.

Upcoming Meeting

- June 17, 2025

Attendance

- **Committee Members**
    - Molly McCarthy, Chair
    - Lorrinda Gray Davis, Vice Chair
    - Patrice Ball
    - Michael Brown
    - Liz DeVivo
    - Tonya Gomez
    - Calvin Henry
    - Robert Johnson
    - Karlett Parra
    - Andreas Price
    - Cathy Ramage
    - Cody Reynolds
    - Michael Slipowitz
    - Steve Weitzen
    - Justin Wilkerson
- **HRSA Staff**
    - Brianna Doby
    - Sarah Laskey
    - Raymond Lynch
    - Heather Myers
    - Mesmain Germain
- **SRTR Staff**
    - Avery Cook
    - Earnest Davis
- **UNOS Staff**
    - Cole Fox
    - Betsy Gans
    - Houlder Hudgins
    - Lindsay Larkin
    - Carly Rhyne
    - Kaitlin Swanner