

**OPTN Patient Affairs Committee
Meeting Summary
May 17, 2022
Conference Call**

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

Introduction

The OPTN Patient Affairs Committee (the Committee) met via Citrix GoTo Meeting teleconference on 05/17/2022 to discuss the following agenda items:

1. Scientific Registry for Transplant Recipients (SRTR) Task 5 Initiative
2. Preparation for 6/21 meeting: Organ Offers
3. Projects recently reviewed by the OPTN Policy Oversight Committee

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

1. Scientific Registry for Transplant Recipients (SRTR) Task 5 Initiative

SRTR staff presented on the Task 5 Initiative.

Summary of discussion:

Members expressed interest in participating in the consensus conference for the Task 5 initiative.¹

The Chair asked what the SRTR hoped to have as an outcome of the consensus conference. SRTR staff responded that they hope for a clear voice from patients and family members of what information is needed and what information they seek to have improved transparency on.

A member praised the work of the SRTR's Task 5 Initiative, but expressed caution that patients do not know, what they do not know, so it may be challenging for patients to identify information that would be useful when they are not aware of what is possible. The member stated that they view the transplant system to be too conservative because medical professionals seek to have successful operations. The member explained this competes with the average patient's goal to be removed from the waiting list by undergoing transplantation.

Another member asked why Native Americans were not included in the Task 5 Initiative focus groups. SRTR staff responded that it was not an intentional exclusion, and that they were unable to have any Native American sign up to participate in the focus groups.

A member asked if the OPTN was supporting the Task 5 initiative financially, and SRTR staff explained that the Task 5 initiative is part of the HRSA contract with the SRTR contractor.

The Vice Chair asked whether the Task 5 Initiative consensus conference will discuss organ offer acceptances on the individual surgeon level. SRTR staff responded that that is information of interest.

¹ For more information on SRTR's Task 5 Initiative, visit: <https://www.srtr.org/about-srtr/the-task-5-initiative/>

A member emphasized that metrics need to be written in plain language for a more generalized understanding from the population as a whole.

The Chair stated that data driven conversations regarding outcomes need to happen with transplant candidates. Another member added that transplant programs need to consider when to have that conversation with a transplant candidate. A member added that it is difficult to educate transplant candidates when they are medically and urgently in need for an organ.

Next steps:

The feedback will be relayed to SRTR staff supporting the Task 5 initiative.

2. Preparation for 6/21 meeting: Organ Offers

The Committee reviewed an overview of the organ offer and acceptance process.

Summary of discussion:

A member that represents the Committee on the Match Run Rules Workgroup stated that this Workgroup has taken a heavy lift in reevaluating and analyzing organ offers and acceptances to improve the system efficiency.

Another member asked whether the Match Run Rules Workgroup is considering the development of continuous distribution framework for organs in their project. A member confirmed the Match Run Rules Workgroup continues to discuss how any changes to organ offers and acceptances may align with the shift to a continuous distribution framework.

Next steps:

The Committee will complete an organ offers educational training in preparation for the June 21, 2022 Committee meeting.

3. Projects recently reviewed by the OPTN Policy Oversight Committee

The Committee reviewed projects recently approved by the OPTN Policy Oversight Committee (POC).

Summary of discussion:

A summary of recently approved OPTN committee projects by the POC:

- Modify Candidate Waiting Time Dates Affected by Race-Based eGFR Calculations (OPTN Minority Affairs Committee & OPTN Kidney Transplantation Committee)

There were no comments or questions.

Upcoming Meetings

- June 21, 2022 (teleconference)
- July 18, 2022 (teleconference)

Attendance

- **Committee Members**
 - Anita Patel
 - Christopher Woody
 - Chris Yanakos
 - Darnell Waun
 - Earl Lovell
 - Eric Tanis
 - Garrett Erdle
 - James Sharrock
 - Julie Spear
 - Justin Wilkerson
 - Justine Van Der Pool
 - Kristen Ramsay
 - Molly McCarthy
 - Sarah Koohmaraie
 - Sejal Patel
- **HRSA Representatives**
 - Arjun Naik
 - Jim Bowman
 - Raleane Skerda
- **SRTR Staff**
 - Allyson Hart
 - Katie Audette
- **UNOS Staff**
 - Kaitlin Swanner
 - Kim Uccellini
 - Lauren Motley
 - Meghan McDermott
 - Sara Rose Wells
- **Other Attendees**
 - Calvin Henry
 - Lorrinda Gray-Davis
 - Steve Weitzen
 - Wendy Leavitt