

**OPTN Patient Affairs Committee
Meeting Summary
May 18, 2021 3:00 – 4:00 PM ET
Conference Call**

**Darnell Waun, R.N., M.S.N., Chair
Garrett Erdle, M.B.A., Vice Chair**

Introduction

The Patient Affairs Committee met via Citrix GoToMeeting teleconference on 05/18/2021 to discuss the following agenda items:

1. Policy Oversight Committee Update and Cross Committee Work Group Updates

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

1. Policy Oversight Committee and Cross Committee Work Group Updates

The Vice Chair provided an overview of the Policy Oversight Committee (POC), which is comprised of the Vice Chairs from each OPTN Committee. Members shared their experience working with workgroups, what to expect when providing the patient perspective to a workgroup of medical professionals, and an overview of each project. Members participated on the Match Run Rules Workgroup and Technology Tools Workgroup.

Data summary:

The POC approves OPTN projects, determines the strategic policy priorities, and is involved in post-implementation evaluation of policies. POC's current strategic policy priorities include efficient matching, multi-organ allocation, and continuous distribution.

Summary of discussion:

Match Run Rule Workgroup

The PAC represent to this workgroup updated the Committee on their work to increase offer filters, develop a dynamic match run, and improve conditional yes offers.

A member added to the discussion around increasing offer filters and contributed their first-hand experience, as a medical transplant professional, with the ways in which this project would save time and make an impact on a successful transplant. Decreasing the cold ischemic time is a step in the right direction and an ideal outcome for this project. A question arose as to how these filters would be impacted when a new surgeon is added to the transplant team, since the historical data is based on a surgeon who may no longer be at the center. The member participating in the work group responded that the pilot filters were very basic, such as height, weight, KDPI score, etc., but centers will have the choice in whether or not they want the filters applied and what their parameters will be.

A member inquired on what the timeline for this project is and how it will be scaled. At the moment, these offer filters are available for transplant centers to use however it is not the default setting and they do not have the option to manipulate the parameters yet.

A member, whom is also a transplant professional, shared their center's practice of meeting monthly to discuss why the center turned down offers and how they can utilize this data to improve. A participant on the call informed the group that CMS and OPTN have regulatory requirements to review the organ offers which they have declined, and supported the idea of developing consistent standards for this practice.

A member inquired what happens when centers do not wish to comply and the member on the workgroup responded that the fluidity of Continuous Distribution should reduce this issue and ensure that organs are matched. The member clarified the concern for patients who are located closely between two regions and choose to double list because one center accepts less organ offers than the other. A member responded that with the move to Continuous Distribution, he hypothesizes it will improve the chance of less aggressive transplant centers to receive more organ offers. An attendee countered that the ongoing role that SRTR metrics plays in a transplant centers ability to accept less than optimal organs will persist in smaller transplant centers. The impact that one bad outcome has on a large transplant center is much smaller than on a small transplant center and there needs to be a way to mitigate this disproportionate impact. Multiple members agreed with this point and the desire to level the playing field for smaller transplant centers. Members expressed interest in getting information from SRTR on whether this was something that has already been explored, and if so, what that data shows.

An attendee suggested developing standard criteria for what is considered a marginal organ, but still expressed concern that ultimately blame of a poor outcome would reflect on the transplant center when the fault was the status of the organ. Members encouraged developing an algorithm that would prioritize the quality of a transplant as opposed to the quantity.

Technology Tools Workgroup

The PAC representative to this workgroup updated the Committee on their work to enhance communications in DonorNet® and increase biopsy image sharing.

A member inquired on the ways in which this project impacts and benefits the patient population. Ultimately, improving the ways in which Organ Procurement Organizations (OPOs) and transplant hospitals communicate to be more efficient will in turn directly benefit the patient who receives that organ. These improvements will increase the overall speed of the organ allocation process.

A member inquired if this project would likely yield a tangible impact on transplant professionals at OPOs and transplant hospitals. The representative for the workgroup shared their personal experience as a transplant professional and the ways in which these projects would directly improve their work and thus positively impact patients. Another member with transplant experience emphasized the importance of being able to have the most accurate donor information and consistent communication standards, especially if it could be done through an automatic notification system.

Furthermore, developing these policies and projects at a national level will allow for consistent and best practices across regions, regardless of what other initiatives OPOs are implementing individually. Ultimately, members felt that this project would improve the technology to allow for the best possible real time communication between OPOs and transplant centers, which is in the best interest of the patient.

Project Work: Multi-Organ Allocation

A member represented PAC on an OPTN Organ Procurement Organization Committee sponsored workgroup which developed a public comment proposal to clarify multi-organ allocation. This work will be continued through the establishment of the Ad Hoc Multi-Organ Transplantation Committee to further this work. The PAC member informed the group that it's a complex conversation that is heavy in

medical information but is an imperative discussion to be having as these policies will impact the sickest patients.

Project Work: Continuous Distribution

An overview of the staggered timeline for this framework implementation was shared as well as the anticipated role the PAC members will have in sharing this information with the patient population. A comment was made by a member that Continuous Distribution should instead be referred to as a points based system for more clarity. In anticipation for upcoming public comment proposals, more information will be shared directly with the Committee and patient population to better inform them of this allocation framework.

Post-Implementation Evaluation

This process will be conducted by the POC to analyze and determine the success of policies and proposals following implementation.

Next steps:

For members whose terms continue past June 30, 2021, please make sure to complete the assigned educational modules in UNOS Connect, as well as the OPTN Conflict of Interest and Confidentially Agreement. Please complete these assignments by June 11, 2021.

Upcoming Meetings

- June 15, 2021
- July 20, 2021
- August 17, 2021
- September 21, 2021

Attendance

- **Committee Members**
 - Anita Patel
 - Chris Yanakos
 - Darnell Waun
 - David Skinner
 - Diego Acero
 - Earl Lovell
 - Eric Tanis
 - Garrett Erdle
 - James Sharrock
 - Julie Ice
 - Julie Siegel
 - Kenny Laferriere
 - Marvin Lim
 - Molly McCarthy
 - Phil Williams
 - Sarah Koochmaraie
 - Stephanie Little
- **HRSA Representatives**
 - Adriana Martinez
 - Jim Bowman
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Abby Fox
 - Laura Schmitt
 - Sara Rose Wells
 - Susan Tlusty
- **Other Attendees**
 - Kristen Ramsay
 - Valinda Jones