

OPTN/UNOS Transplant Coordinators Committee (TCC)
Meeting Minutes
December 19, 2018
Conference Call

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Introduction

The Committee met via Citrix GoToTraining teleconference on 12/19/2018 to discuss the following agenda items:

1. UNOS Staffing Changes
2. Committee Reports
3. 2019 Learning Series Prep & Planning
4. OPTN/UNOS Board of Directors Debrief

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

1. UNOS Staffing Changes

UNOS Staff will discuss a new staff model and introduce new staffing for the TCC Committee.

Summary of discussion:

UNOS staff reminded the committee that an email from UNOS was sent discussing how the Policy and Regional Administration departments have merged, in an effort to better serve our volunteer workforce. Moving forward all OPTN committees, including TCC, will have three people supporting each committee. This includes the Transplant Community Administrator (TCA), Policy Analyst, and Policy Associate. Consequently new staff members were introduced to the committee.

2. Committee Reports

Two public comment proposal previews will be presented to the TCC committee members.

Data summary:

1. Eliminate DSA from Thoracic Distribution

The Committee received a presentation and provided feedback on the Thoracic Committee's *Eliminate DSA from Thoracic Distribution* proposal. An overview was discussed and highlighted that the use of Donation Service Area (DSA) as a unit of distribution in heart allocation is not consistent with the OPTN Final Rule and therefore changes had to be made. The solution presented was to replace DSA with 250 nautical mile (NM) circles from the donor transplant center. The proposed policy changes included the policies listed below. The changes were to remove DSA and zone and add the 250 NM as needed.

- OPTN/UNOS Policy 1.2 Definitions
- OPTN/UNOS Policy 5.10.C Other Multi-Organ Combinations
- OPTN/UNOS Policy 6.4.B Exceptions to Allocation for Sensitized Patients
- OPTN/UNOS Policy 6.6.D Allocation of Hearts from Donors at Least 18 Years Old & 6.6.E Allocation of Hearts from Donor Less Than 18 years old
- OPTN/UNOS Policy 10.4.C Allocation of Lungs from Deceased Donors at Least 18 Years Old & 10.4.D Allocation of Lungs from Deceased Donors Less than 18 Years Old.

2. Guidance on Effective Practices for Broader Distribution

The Committee received a second presentation and provided feedback on the Operations and Safety Committee's *Guidance on Effective Practices for Broader Distribution* proposal. An overview was discussed, and highlighted that with the removal of DSA and region as defined units of distribution, it will result in new recovery and transplantation practices. Several solutions were proposed such as the need to identify effective practices and lessons learned, consultation with subject matter experts, stakeholder and OPTN staff, and to provide resources to help efficiently allocate organs across broader geographical area.

A variety of topics were included in the guidance document. Some mentioned were transportation resources, Histocompatibility considerations, streamlining communications, organ procurement surgeon models, procurement team staffing models and several more not listed here.

Summary of discussion:

Eliminate DSA from Thoracic Distribution

The Committee questioned if at this point in the policy development process there was an opportunity to suggest changes. Staff stated that the Thoracic Committee had already voted on the proposal, however UNOS staff would like feedback on whether 150 NM or 250 NM is the most beneficial distance, and would also like a rationale for that answer. Another member also asked if there were any unique aspects to the thoracic proposal that members should be made aware of. Staff responded by saying no and reminded the committee the history of why these changes are being proposed and the classifications changes that were included in that. Several committee members had a lengthy discussion on multi-organ transplant (MOT) policies and expressed their concern on what the impact of broader sharing and communication will have on the transplant community and the quality of transplants. Members shared a concern about the status/priority of MOT policies for the OPTN, and staff responded by stating that it is a priority of the OPTN and that the Ethics Committee is developing a white paper on MOT. Other concerns that were raised were on MOT patient priority and primary organ versus secondary organs. Specifically UNOS needs to create a policy or guidelines of some kind to help in complicated situations that may arise in broader organ sharing across state lines. Lastly several members shared a problem they can see happening in future in terms of communication. More specifically in the manner in which teams are communicating with this broader sharing and made a request of UNOS to work on developing mechanisms and/or tools to help with this communication.

Guidance on Effective Practices for Broader Distribution

The Committee asked, if in addition to the guidance document, are there currently any tools in development that will enhance communication, tracking of teams, modifications of OR times, cross clamp times? UNOS staff responded by stating that there are no tools currently in production, however would like feedback from the committee on what information can and wants to be shared, what does or not does not warrant a notification in DonorNet and how the notification process should occur. Subsequently, they asked UNOS staff if there is a subcommittee or work group working on this? Staff indicated there is not at the moment however, if members are interested, please alert UNOS support staff.

Next steps:

UNOS staff will provide the Ethics Committee white paper on MOT for members to read and to send their comments/thoughts to UNOS staff and staff will work together with committee members to compile a statement from the TCC Committee for public comment.

UNOS staff will send out an email asking for volunteers from the TCC Committee to participate in a work group with UNOS IT department on developing a communication tool.

3. 2019 Learning Series Prep & Planning

UNOS Staff provided an update on the most recent addition to the learning series and future plans for the 2019 year.

Data summary:

UNOS staff reminded the Committee that the most recent installment of the TCC learning series, Explaining the Waitlist, was posted on December 5th, 2018. Staff encouraged members to take a look at that series and explained how to navigate to the offering. Also mentioned was a staffing change in the Professional Education department for the TCC learning series project. New staff was introduced. Staff alerted the committee that plans were in development to start the learning series in the beginning of 2019. UNOS staff reminded the committee that it had a list of topics and is aware of the priorities of the committee. Currently, more research is being done on these topics to become more familiar and that there are plans to meet with the UNOS internal team to discuss the next steps. Lastly highlighted that, in December 2018 and January 2019 there will be communications coming out of UNOS Connect with a summary of all the offerings listed. A request of the TCC Committee was made, stating that if your members hear relevant topics or topics that your colleagues are concerned about, of which UNOS has a resources for, please point those out to them. If not, let UNOS support staff know so we can do the research needed to address that topic/issue.

Next steps:

Professional Education staff will set up a meeting with UNOS internal team to discuss the 2019 TCC learning series.

4. OPTN/UNOS Board of Directors Debrief

UNOS Staff provided the Committee a recap from the December 2018 Board of Directors (Board) meeting.

Data summary:

UNOS staff highlighted some key points that the Committee should be aware of following the Board meeting. The Ad Hoc International Relations Committee provided their annual report about non-US resident transplant activity. The Board wanted a further deep dive into this information in the future. Two breakouts occurred 1.) evaluation collaborative improvement effectiveness: the good, the bad and the ugly and 2.) organ perfusion emerges from the niche. Lastly the Board approved nominees for vacancies.

In terms of OPTN/UNOS policy, the consent agenda was passed which included *Change to Hospital-Based OPO Voting Privileges, Pancreas Program Functional Inactivity, Tracking Pediatric Transplant Outcomes Following Transition to Adult Care and Addressing HLA Typing Errors*. On the discussion agenda was the Liver proposal which involved a lengthy discussion which ultimately resulted in the approval of the Acuity Circle framework. Out of the three geography frameworks outlined in the proposal, continuous distribution was approved by the Board. The last proposal was the *Change to Islet Bylaws* which was discussed briefly, but ultimately approved. Lastly there was a Thoracic Committee update more specially a nine month lung monitoring report, as well as a geography update from the Kidney and Pancreas work group.

Finally, the OPTN/UNOS President presented some highlights from the survey and themes of the constituent council project. This survey was then shown to Committee members. The survey

asked: “As a clinical transplant coordinator constituent council member, how do you think we should proceed with the proof of concept?” The results were equally split with 5 votes between the choices of 1. *Continue as-is but reconsider the committees involved* and 2. *Consider revisions to the concept, but continue testing ways to increase cross committee and Board communication*. The remaining choices had only a few votes. Three for wanting to *end the project*. Two for both *Continues as is but add more individuals* and for *Continue as is giving it more time for everyone to acclimate*. The Board recommended to keep this proof of concept for Patient Affairs Committee (PAC) and to remove TCC. Staff explained that this decision means that members are no longer obligated to call and participate, but if members would like to, they are free to do so. In addition members were made aware that Basecamp going forward may not be the communication method used by UNOS staff. Staff also asked members “Due to the low response on the survey UNOS leadership would like your feedback on why you think the restructure didn't work with coordinators?”

Summary of discussion:

The Committee responded to UNOS staff question in regards to the constituent council project (Due to the low response on the survey UNOS leadership would like your feedback on why you think the restructure didn't work with coordinators?) and several members had a similar response. They expressed that there was a lack of structure and expectations on what they were to accomplish. There were no helpful ways on how to proceed with meetings, what to provide in terms of feedback to other committees.

Other members discussed that they professionally identified with the Committee easier, but emotionally with PAC group due to its nature of being patient based. Some believed that this project worked well for the PAC group and provided alternative resources and insight. However, other members disagreed and stated that they believed the transplant coordinators community has a strong voice, is very active in their feedback and is well represented on other committees. Other members disagreed with the representation point, they believed that certain committees had a lack of transplant coordinators representation on the committees.

Lastly a member commented by saying that that the goals and measurements of success for increased engagement had changed over a period of time due to the elimination of DSA and geography. They believed it began to overshadow the constituent council project, and the goals they were trying to achieve. What was appreciated by members was when coordinators on other organ committees sat in on the in-person meeting to keep TCC group updated on what projects are going on. However there was concern that there is a lack of transparency from UNOS and the policy development process of proposals.

In terms of communication, members questioned if they should use a different format of communication through Basecamp and remarked that as “transplant professionals, we are very cautious on what we state on different platforms, they represent ourselves, UNOS and our transplant programs”.

UNOS staff listened to feedback and thanked the committee for their thoughts.

Next steps:

UNOS Policy and Community Relations staff will take the comments made by the committee and bring them to leadership.

Upcoming Meeting

- January 16th, 2019 Full Committee Conference Call
- February 19th, 2019 In-Person Committee Meeting in Chicago, IL