OPTN/UNOS Transplant Coordinators Committee
Meeting Minutes
September 13, 2018
Chicago, IL

Sarah Nicholas, RN, Chair
Sharon Klarman, RN, Vice Chair

Introduction

The Transplant Coordinator Committee (TCC) met in Chicago, IL on 09/13/2018 to discuss the following agenda items:

1. Public Comment Proposal Review Case Review
2. Improving the OPTN/UNOS Committee Structure through Enhanced Communication and Engagement Proof of Concept
3. Learning Series Needs Assessment

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

1. Public Comment Proposal Review Case Review

The TCC reviewed the following proposals and provided feedback.

Pancreas Functional Inactivity

The TCC appreciates the Pancreas' Committee's efforts to improve waitlisted patient and transplant recipient outcomes by creating new thresholds for identifying functionally inactive pancreas programs that operate below the level that is adequate for their waitlisted candidates. The group concurred that the policy revision addresses not only reducing unnecessary work for the MPSC but maintains and patient safety and will hopefully improve patient access.

Members agreed that it was more reasonable to look at inactivity on a yearly basis especially given the relative short waiting time for pancreas. Changing the definition for functional inactivity from "< 1 in 6 months" to "< 2 in 12 months with above average wait times" will reduce the MPSC's need to review pancreas programs based on low volume alone.

The requirements under the new proposal for programs to notify patients is a patient-centric solution that will require programs to give patients the information they may need to make informed decisions about getting on the wait list at a more active program with lower wait times. The additional step to require transplant center to provide not only alternative centers but the waiting time comparison of inactive program to national average will hopefully help address patients that are not transferring after program inactivity, improving their access to transplant.

One Committee member did advise that the national waiting time average may not be the best metric, as there will be a lot of variation. Median waiting time by region might make more sense, as they are pulling from the same donor pool. Another metric suggested to the Pancreas Committee was organ offer acceptance rate. Programs should not be penalized if they are not getting organ offers. Another Committee member opined that for pancreas allocation, OPOs have some discretion when it comes to how they allocate pancreata-whether multi-visceral offers pan out, non-local offers, etc. Policy should be more stringent around pancreas allocation.

The group supported communicating additional information to candidates listed at a functionally inactive program, but advocated that each of the organ-specific committees should decide whether that is appropriate. If so, they should also decide what information to communicate.

One member supported providing SRTR data (beta site) to patients, to capture not only programs doing more transplants, but programs who transplant similar phenotypes of patients.

The following questions were asked and answered to the satisfaction of the TCC:

- **Q: When classifying pancreas programs by volume, did the Pancreas Committee look into whether the center also had a small volume kidney program, or perhaps a large volume kidneys program, and maybe the center wasn't prioritizing their pancreas program?**
  A: The Pancreas Committee did not look into whether a pancreas program was part of a center with a large or small kidney program.
- **Q: Does CMS have similar patient notification requirements that could be mimicked for these purposes?**
  A: The presenter was not aware of CMS requirements around transplant thresholds, for pancreas in particular.

Models of Geographic Distribution

The TCC thanks the Ad Hoc Geography Committee for the opportunity to comment on various geographic distribution frameworks to inform future allocation policy more consistent with the OPTN Final Rule.

There was consensus around support for the continuous distribution model. The TCC felt is seemed to be the most in alignment with the demands and requirements of the Final Rule, and that it has the most potential to work for all organ groups. The medical priority and proximity scores will need to be developed from the clinical characteristics for each organ type. These characteristics can be more easily adjusted or weighted differently as the model is reviewed and not alter the entire distribution process. However, there needs to be consideration for donor families and efficiency; there cannot be major time delays that may impact a donor family's decision to donate.

The TCC expressed concern about disadvantaging candidates who lack resources (whether monetary, insurance, or location) and smaller programs being forced to close due to increasing costs of organ allocation and other factors that may not impact larger programs in the same fashion. In addition, they advised that following outcomes is going to be critical in evaluating any framework, as one of the overarching goals is to transplant the most medically urgent patients first. One member advised that modifying organ distribution systems, without consideration for fiscal impact, will have negative implications for transplant program bottom lines, especially if insurance providers don't also make adjustments.

The following questions were asked and answered to the satisfaction of the Committee:

- **Q: Isn't the fixed distance framework still dependent on geography? How does that pass muster legally?**
  A: This model was deemed to be more consistent with the Final Rule than DSA or region, but may not be the most consistent. It is the model that was determined to be easily implementable within the stringent timeframe mandated by HRSA.
- **Q: For the continuous distribution model, is the medical urgency score weighted, compared to the other two variables?**
  A: It is too be determined how the variables would be weighted.
- **Q: Is waiting time being considered with any of these models?**
  A: It has not been determined whether waiting time will be incorporated in any of the models, or play a role beyond what it currently plays. That decision may be organ specific.

- **Q: How does this proposal dovetail with the work the organ-specific committees are currently undertaking? If the community feels that continuous distribution is the best model, how does that impact the other proposals?**
  A: Based on the aggressive timeline for the organ-specific committees to modify their distribution systems, the fixed distance model was deemed to be most feasible. The framework that receives the most support may be considered a more ideal "future state".
- **Q: With organ acquisition costs increasing, along with travel and logistics expenses, occurring in the middle of a budget cycle, transplant programs are having to make cuts. How is fiscal impact to transplant programs being considered?**
  A: Cost and efficiency align with one of the organ distribution principles (that in turn align with the Final Rule) approved by the Board of Directors in June 2018. That being said, it has been extremely challenging to source transplant center financial data to support limiting geographic distribution for financial reasons. The OPTN Operations and Safety Committee in conducting an industry questionnaire to get at some of the data the OPTN does not collect, but it is obviously limited to the current distribution systems. A Committee member advised ASTS and ASTS may also be looking into this.
- **Q: Will the distances of the circles vary depending on where the donor is, i.e. Alaska, Hawaii, and Puerto Rico?**
  A: No, but the non-contiguous states are a special circumstance. The Geography Committee discussed these outliers and determined not to make a change at this time.
- **Q: What about OPO's who use organ recovery centers? Will the circle originate at that location?**
  A: No, circles originate at the donor hospital.

<u>Tracking Pediatric Transplant Outcomes Following Transition to Adult Transplant Programs</u>

The TCC thanks the Pediatric Transplant Committee for the opportunity to provide feedback on their guidance document regarding transitioning and transfer of pediatric recipients to adult care.

The TCC supports the intent of this guidance, however, there needs to be consideration for a coordinator's time, and reimbursement. The extra time and care provided to transitioning patients is not reimbursable. Although pediatric programs are likely very supportive of these recommendations, this is still a concern, and likely more so on the adult side. Therefore, the TCC might support a policy initiative, should that be proposed in the future.

Members shared practices from their institutions. One member shared that patients are encouraged to use the patient portal/MyChart to get them use to their medical information. In addition, a patient advocate for transitioning pediatric patients was suggested (i.e. dedicated social worker or coordinator). Another member shared they had a dedicated adult coordinator who handled transfers from the pediatric abdominal program. That staff member would brief adult provider staff on upcoming transfers, and has proven to be an effective practice. This institution also has the adult coordinator attend the last pediatric appointment, and has the pediatric coordinator attend the first adult program appointment.

2. Improving the OPTN/UNOS Committee Structure through Enhanced Communication and Engagement Proof of Concept

The TCC discussed the progress of the proof of concept and provided feedback. The TCC is operating under the moniker "Clinical Transplant Coordinator Constituent Council" (CTCC) for the duration of the proof of concept.

Data summary:

To assess current engagement levels amongst transplant coordinators within the OPTN committee system, constituent council members completed a baseline survey. Responses to qualitative questions are captured in **Exhibit A**.

Less than half responded to the survey, but indicated 1-3 years of experience, spending 2-4 hours a month to an OPTN Committee consisting mostly of Committee calls or meeting preparation.

- The majority agreed or strongly agreed that:
    - UNOS staff made them feel their role was important and value
    - Volunteer leadership made them feel important
    - They were called upon to offer perspectives during Committee discussions
    - Felt comfortable speaking up to offer their personal transplant coordinator perspectives
    - Felt comfortable speaking on behalf of transplant coordinators more generally
    - They could explain my Committee's projects and policy proposals
    - The transplant coordinator voice is well represented in the policy development process
    - Transplant coordinators participate in the OPTN policy development process

On a scale of 0-100, members were asked to rate their engagement level and provide comment explaining their score. Ratings ranged from a low of 39 to a high of 100. Responses to this question can be found in **Exhibit B**. Respondents indicated they express opinions all the time to occasionally or infrequently. No one indicated they never speak up.

TCC members provided feedback through an audience engagement polling application, generating a word cloud based on common sentiment. UNOS staff then presented the statement, “This proof of concept is…”. The feedback was analyzed and feedback grouped according to whether the feedback was positive, neutral or negative:

Positive	Neutral	Negative
Capable of extruding more ideas and participation	Not relaying the full need of participation	Frustrating
Promotes interactions between groups	Lifeline	Confusing
Good idea	Repetitive	Not well defined
Acceptable	A way to “prove” that the change of committees is positive thing although most regions were against the change	Politically motivated
Provided opportunities for inter-committee interaction	Overshadowed by the geography project	Unclear end goal
Innovative	Still not sure how this will matter to the big picture	Increase disengagement
A good way to get our voice out	A starting place	Somewhat worrisome that we will be less heard

Positive	Neutral	Negative
Wonderful	Ever changing	Going to shift work onto fewer people
Interesting	Theoretically beneficial	Complicated
Engaging	Vague	Time consuming
Overall good	New	

Later in the discussion, members provided feedback on Basecamp, an online team collaboration and communication tool being piloted to serve as a repository for meeting materials and a platform to continue real-time dialogue between meetings. UNOS staff presented the statement, “Basecamp is…”. The feedback was analyzed and feedback grouped according to whether the feedback was positive, neutral or negative:

Positive	Neutral	Negative
Good if used for the right reasons	A chat app	Steep learning curve
Great communication tool	Mobile friendly	Busy
Good for project tracking	Duplication	Time consuming
Easy to use	A platform for discussion	Not useful
Better than SharePoint	Interesting	Too much
A tool that can bring ideas together	Low priority	Too many emails
		Frustrating
		Not user friendly
		Cumbersome
		Annoying
		Overwhelming
		Confusing

An analysis of the TCC Basecamp site was conducted, revealing that there is little dialogue between Committee members. In addition to utilizing Basecamp similar to how Committees use SharePoint (as place to find meeting files, policy proposals and project resources, slides and meeting minutes from meetings, etc), the goal of trialing this platform was to see whether it could support and facilitate real-time dialogue. It would be used for obtaining feedback on policy projects early in development.

Summary of Discussion

The TCC discussed the proof of concept. There was a comment that each Committee member brings their own expertise and she was concerned about the transplant coordinators' input being heard when there are two very different groups in the pilot. The TCC felt that joint committee project workgroups fulfilled the need to solicit coordinator feedback earlier in the policy development process, versus manufacturing a process there is no need for. There must be transparency of what everyone is working on, so the TCC knows what it could be involved in. There is room for improvement in terms of communication.

The TCC delved into a discussion on Basecamp. One Committee member felt the responses regarding Basecamp would be different depending on what aspects of the tool are being focused on. It is a good tool compared to SharePoint, but will depend on utilization and whether it will be used for chatting engagement or for sharing documents/projects/learning. Some Committee members felt Basecamp was annoying and another thing to check, but that might be an issue with training and just how to use notifications. One member did not want to turn off notifications because she was afraid to miss something important if she did. UNOS staff noted

that in addition to posting training videos on Basecamp, a mini tutorial was done on one of the monthly conference calls. Members indicated reading updates on Basecamp is time consuming. One Committee member felt it is distracting and she does not know what to focus on when updates come quickly and often. In addition, the group felt they were getting responses from topics that are irrelevant to them.

Members noted that professionals are hesitant to express opinions on the Internet, not matter whether or not the forum is private or not. Therefore, engagement should not be measured by simple responses posts. If someone doesn't post, it doesn't mean they're not reading.

In addition, one Committee member expressed hesitancy to ask a specific question because she did not know the knowledge base of everyone accessing the webpage or how informed they are about the topic. It might better to use a listserv, rather than opening it up to everybody, in fear of getting responses from people who are uninformed about the topic.

Next Steps:

The project is a work in progress. Feedback from the Committee is welcome at any time.

3. Learning Series Needs Assessment

The TCC brainstormed education topic ideas for the 2019 learning series. Below is a comprehensive list of ideas; the bolded topics were prioritized.

- **Explaining SRTR reports and data to patients**
- **Social work SIPAT tool-risk score for a subjective area of the evaluation process**
- **Infectious disease series – common infections; immunization; managing flu season, travel history**
- **Why TIEDI? Explaining why data is important, what fields mean, etc. how it feeds risk/why unknown is bad, how to answer subjective q's**
- **UNOS site survey preparedness/most common citations/resources/source documents for validation of compliance with policy (tie)**
- **Terminology crosswalk-tx coordinator/OPO coordinator terms/glossary: speaking different language (e.g.: Virtual crossmatch, primary, backup, local) (tie)**
- Best practices of EMRs in transplant—site surveys, clinical practice
- Pharmacology series – immunosuppression medication and prophylaxis medication
- Procurement education – reading biopsy slides; interpreting H&P; interpreting ECHO results; HLA cheat sheet; Maximizing organ potential without sacrificing organs
- Allocation changes—education for each organ allocation change
- Policy development 101 for coordinators and patients
- Best practices in outreach programs
- Compassion Fatigue
- Coordinator retention/staffing
- Increased risk donors
- Use of Hep C donors+/recip -
- Protocols/followup of tx high-risk liver candidates
- Living donor/recipient conversations (best practices, addressing the communication; confidentiality, etc)
- HLA series – PRA, DSA, MFI
- Utilize prediction calculators (e.g.: chances of getting an organ offer)

Upcoming Meeting

- October, 2018