

Meeting Summary

OPTN Transplant Coordinators Committee Meeting Summary February 26, 2020 Chicago, IL

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Introduction

The Transplant Coordinators Committee met in Chicago, Illinois on 02/26/2020 to discuss the following agenda items:

- 1. TCC Learning Series Update
- 2. OPTN OPO Committee: Modifications to Released Kidney and Pancreas Allocation
- 3. OPTN Minority Affairs Committee: Data Collection to Assess Socioeconomic Status and Access to Transplant
- 4. OPTN IT Update
- 5. OPTN Operations and Safety Committee: Modify Blood Type Determination and Reporting Policies & Guidance on Blood Type Determination
- 6. Communications Focus Group
- 7. OPTN Kidney Transplantation Committee: Addressing Medically Urgent Candidates in New Kidney Allocation Policy Discussion
- 8. OPTN Kidney Transplantation & Pancreas Transplantation Committees: Distribution of Kidneys and Pancreata from Alaska
- 9. OPTN Committee Workgroups: TCC Member Updates
- 10. Open Forum: Effective Practices Discussion

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

1. TCC Learning Series Update

UNOS Professional Education presented on the status of the TCC Learning Series.

Data summary:

Slides attached.

Summary of discussion:

Committee members agreed that it has been very helpful for them to orient new hires at their institutions.

Next steps:

The Committee is discussing effective practices, and will identify potential topics for future episodes of the learning series.

2. OPTN OPO Committee: Modifications to Released Kidney and Pancreas Allocation

UNOS Kidney and Pancreas Committee liaisons presented the proposal currently out for public comment.

Data summary:

Slides attached.

Summary of discussion:

The Committee believes that kidneys and pancreata should not be reallocated in the same manner, since pancreata are much more sensitive to cold ischemic time. The Committee believes that it would be most helpful to have a local backup for the organs, and result in fewer organ discards and greater efficiency in organ reallocation.

7 yes; 5 no; 3 abstained.

3. OPTN Minority Affairs Committee: Data Collection to Assess Socioeconomic Status and Access to Transplant

OPTN Minority Affairs Committee Representative presented the proposal currently out for public comment.

Data summary:

Slides attached.

Summary of discussion:

The Committee agrees that there is need to better determine how socioeconomic status impacts transplantation, and that the data that is currently collected by the OPTN is insufficient to do so. However, the Committee has many concerns about the proposal's method of addressing this inequality. There is already a difficulty in obtaining patient trust in the transplantation process, and many patients are already concerned that a low socioeconomic status could negatively impact their ability to receive an organ offer. This could create a large bias in the information that is reported, and could potentially lead to a decrease in lower socioeconomic status patients being listed for transplant due to patient distrust. The Committee is also concerned about the data needing to be adjusted for cost of living, as well as the data being updated as household income fluctuates, and this proposal only addresses data collection at time of listing. In addition, this data would not fully address the issue of access to transplant, since this would not include patients who are unable to be listed for transplant at all due to inability to travel to appointments, lack of support, and inability to pay for medications, which is largely impacted by socioeconomic status.

0 yes; 10 no; 2 abstained.

Next steps:

OPTN Minority Affairs Representative will bring these concerns to the Committee.

4. OPTN IT Update

UNOS IT staff presented on the statuses of OPTN IT projects the committee had expressed interest in.

Data summary:

Slides attached.

Summary of discussion:

Committee members reviewed the current changes being implemented by UNOS and had the following suggestions:

- More discrete data fields to be available in DonorNet and Waitlist, especially kidney pump time and warm ischemic time for DCD organs, and the ability to sort by these filters
- The ability for a center to filter their candidates for a specific organ by different acceptance criteria, to make a targeted group of candidates
- A revision of offer decline codes for more granular responses, especially code 830
- The ability to enter NLRB data from a mobile perspective, especially MELD labs
- More discrete data fields for specific PHS increased risk factors instead of just a yes/no
- Un-blinding center names on match runs for accepting centers, to know how many centers are in front of a given candidate, not just how many candidates are
- The ability to opt into specific updates on organ offers, sent in real time, able to be modified if the accepting center is primary or not
- Availability to have donors a center is following at the top of the page in Waitlist, instead of having to scroll through to find them
- Adding a link from the match run for a donor to remove them from DonorNet post-transplant
- Expanding temporary inactivation (status 7) reason codes for more data on how to better manage patients, since current codes do not sufficiently capture reason for removal, and don't account for lack of healthcare access in low socioeconomic status patients

Next steps:

UNOS IT staff will take the committee's suggestions back to UNOS IT leadership to evaluate their feasibility and potential for implementation.

5. OPTN Operations and Safety Committee: Modify Blood Type Determination and Reporting Policies & Guidance on Blood Type Determination

OPTN Operations and Safety Committee Representative presented on two current proposals out for public comment.

Data summary:

Slides attached.

Summary of discussion:

The Committee is highly supportive of this proposal. Their only concern was addressing any potential changes to the site survey process.

13 yes; 0 no; 0 abstained.

Next steps:

OPTN Operations and Safety Committee Representative will discuss with the committee if there will be any additional changes to the site survey process, but none are anticipated at this time.

6. Communications Focus Group

UNOS User Experience Analyst led a focus group to identify methods to improve communication with the transplant community on the OPTN website.

Data summary:

Communications asked the committee a series of questions on reception of media and transplant news, and the best way to deliver information to transplant coordinators and their patients via the OPTN website.

Summary of discussion:

The committee would like to see more information on the OPTN website about the following:

- New tools or offerings on the UNOS data service portal
- Media on current news in transplantation
- A podcast, and especially one focused on current policies under development
- A place to see professional affiliations available and a short synopsis on them
- Explanations of surgery process for newer coordinators, especially living donor surgeries
- Videos or podcasts on policy in practice, collaborating with MPSC on opportunities to learn a more efficient and successful process
- Notifications when an old policy is no longer effective

The committee is also interested in patient education resources, in a video format and in multiple languages, on the following topics:

- SRTR data
- Explaining the Waitlist
- Explaining PHS increased risk factors
- Donor profiles, e.g. serologies, DCD, brain dead
- HLA and tissue typing
- Connecting to a donor family emotionally
- A donor family and recipient discussing how they wrote their first letter

The committee is interested in a UNOS-centered patient platform to connect to other patients, who have had similar experiences.

Next steps:

UNOS Communications will discuss the feasibility of these ideas and ways to make the OPTN website more useful for coordinators and patients.

7. OPTN Kidney Transplantation Committee: Addressing Medically Urgent Candidates in New Kidney Allocation Policy Discussion

OPTN Transplant Coordinators Committee member presented to the rest of the committee on the current proposal out for public comment.

Data summary:

Slides attached.

Summary of discussion:

The Committee believes that a uniform policy on medical urgency designation in potential kidney recipients is imperative with the implementation of broader sharing. However, the committee is concerned about the strictness of the medically urgent definition proposed. The Committee is concerned that a candidate who only has transhepatic or translumbar dialysis access would be unable to undergo transplant due to lack of venous access for surgery. The Committee instead proposes having two vascular surgeons independently verify lack of venous access and provide source documentation. The Committee is also concerned that the severity in the definition of medical urgency does not fit with the allocation system proposed, and that medically urgent candidates should not fall behind living donors and pediatric candidates in allocation, including with low KDPI kidneys. The Committee also

believes that there is potential for exceptions in medical urgency, and that a prospective review board would be helpful to review potential exceptions for increased equity in the allocation system.

Next steps:

UNOS liaison is taking the committee's concerns to the Kidney Transplantation Committee for their review.

8. OPTN Kidney Transplantation & Pancreas Transplantation Committees: Distribution of Kidneys and Pancreata from Alaska

UNOS staff presented the joint Kidney and Pancreas Committee proposal currently out for public comment.

Data summary:

Slides attached.

Summary of discussion:

The Committee is unanimous in support of this proposal and has raised no concerns.

9. OPTN Committee Workgroups: TCC Member Updates

TCC members serving as liaisons to other OPTN committees presented updates on their collaborative work.

Summary of discussion:

Committee members collaborating with the Ethics, Living Donor, and Ad Hoc Disease Transmission Advisory Committees shared their experiences and initiatives.

Next steps:

UNOS liaisons will reach out to committee members about further collaboration opportunities.

10. Open Forum: Effective Practices Discussion

The Committee chair opened the discussion for members to share their effective practices that may not be in wider use.

Summary of discussion:

Committee members discussed the following practices:

- Optimizing the use of EMRs to capture Waitlist data and the profiles of comorbidities
- Using at-home health care companies to follow up with living donors, since there is an issue of
 getting accurate data on far away donors, or with donors traveling back to the transplant
 program
- Using telehealth for 6 month follow ups, especially for patients with limited access or who are not as adherent
- Staffing quarterly transition clinics with an attending physician, transplant coordinator, pharmacist, adolescent physician, and psychologist, that way there is an established transition and relationship so the patient isn't lost to follow ups
- Best practices for data entry, to discuss with transplant administrators
- Combining the Organ Procurement and Transplant Coordinators Committees for once yearly meetings, since they request so much feedback from each other

• Transportation of organs, especially with livers and broader sharing. Possibly tracking the data more granularly, especially about financials

Next steps:

The Committee would like to discuss using some of the ideas to create further TCC learning series episodes. They also would like one member to present a practice at each conference call, to discuss in greater detail.

Upcoming Meetings

- March 18, 2020 Teleconference
- April 15, 2020 Teleconference