OPTN/UNOS Transplant Coordinators Committee

OPTN/UNOS Transplant Coordinators Committee
Report to the Board of Directors
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Atlanta, Georgia

Laurel Williams-Salonen RN, BSN, MSN, Chair
Jamie Bucio, EMT-P, CPTC, Vice-Chair

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This report reflects the work of the OPTN/UNOS Transplant Coordinators Committee from October 2014 through March 2015.

**Action Items**

None

**Committee Projects**

1. **Proposal to Notify Patients Having an Extended Inactive Status**

   **Public Comment:** March 14 – June 13, 2014

   **Board Consideration:** N/A

   The goal of the proposal was to promote effective and safe patient care, increased patient access to transplantation and assure patients are aware, on a regular basis, that they cannot receive an organ transplant while on an inactive list and allow them to be proactive in their plan of care.

   Based on responses received during the public comment period, the Committee did not submit the proposal to the Board in November 2014. Instead, the Committee formed a Patient Notification Work Group. The goal of this Work Group is to develop effective patient notification and waitlist practice articles and educational materials for professionals and patients. The Work Group created a survey that will be used to study real-world practices, timing, and communication related to listing and managing candidates at an inactive status (Status 7) on the waitlist. The survey results will be used in the development of effective patient notification and inactive waitlist management practices for the transplant community. The survey was distributed to transplant coordinators on February 20, 2015 and closed on March 13, 2015. The Work Group will review the survey results in May and begin to develop interview questions to use for effect practice articles.

2. **Operations and Safety Committee (OSC) Infectious Disease Verification**

   The Transplant Coordinators Committee (TCC) has two representatives assigned to the OSC Infectious Disease Verification Work Group. The representatives for this Work Group provide feedback on the verification/confirmation of infectious disease results pre-transplant to help assure that recipients do not receive infected organs accidentally. For more information, see the OSC Report to the Board.

3. **Organ Procurement Organization Committee (OPO) Limit Paper Documentation Required to be Shipped with Organs**

   The OPO Committee requested feedback from the TCC on how to reduce the amount of paper documentation that gets packaged and shipped with organs. The main focus of the OPO Committee’s discussions is to simplify the process and only require OPOs to package and ship the essential information with each organ and allow for the remaining information to
be uploaded into DonorNet®. The OPO Committee was seeking input from the transplant center community to ensure that all steps in the process are identified and addressed. For more information, see the OPO Committee Report to the Board.

4. Living Donor Committee (LDC) and Operations and Safety Committee (OSC) Potential New Requirements for the Transport of Living Donor Organs Project

This joint project is using Healthcare Failure Mode & Effect Analysis (HFMEA) to evaluate failure modes for the transport of living donor organs. Three TCC members volunteered to participate in this project and will provide progress updates to the full committee on its monthly web conferences and in person meetings. For more information, see the LDC and OSC Reports to the Board.

5. Patient Affairs Committee (PAC) What Every Patient Needs to Know (WEPNK) Brochure Updates

The TCC decided that the proposal to notify patients having an extended inactive status should not be presented to the Board this past November based off of responses received while out for public comment. Instead, the Committee decided to educate the community and patients about what it means to have an inactive status. One of those educational efforts included partnering with the PAC on revising the waiting list section of WEPNK brochure and adding a section on what it means to be inactive. The brochure was finalized in March 2015. For more information, see the PAC Report to the Board.

6. Ethics Committee Proposed Project to Consider if Living Donor Recovery Hospitals Should Be Responsible to Provide Care for Post-Operative Complications

The Ethics Committee requested the TCC’s feedback on if living donor recovery hospitals should be responsible for the providing care for post-operative complications. Currently OPTN policy does not address responsibility for potential post-operative complications in living donors. As currently envisioned, this proposed project could lead to the development of a white paper or some other type of voluntary guidance resource. This proposed project will not result in proposed policy to require that living donor recovery hospitals provide care for post-operative complications.

TCC members agreed to talk with the living donor coordinators at their centers about the number of live donor complications they have had and their follow up procedures. All responses received were communicated to the Ethics Committee liaison. For more information, see the Ethics Committee Report to the Board.

Committee Projects Pending Implementation

None

Implemented Committee Projects

7. Tiedi® Help Documentation

Public Comment: N/A
Board Approval: N/A
Implementation Date: October 15, 2014

The role of this Tiedi® Subcommittee was to make recommendations that would improve the accuracy and the completeness of data by reviewing the documentation that exists in the Tiedi® help documentation. The group clarified what data needs to be entered into the forms...
for accurate/complete data to be collected and provided recommendations on how to educate users.

The Subcommittee recommended that all currently optional fields be deleted within the Tiedi® forms and this recommendation was incorporated with the 2015 OMB updates. The Subcommittee’s questions and suggested revisions to current fields will be considered by the Data Advisory Committee (DAC) and recommendations for non-substantial deletions were made without referring back to committees.

Review of Public Comment Proposals

The Committee reviewed eleven of the 28 policy proposals from September 2014 – March 2015.

8. Proposal to Implement Pre-Transplant Performance Review (Membership and Professional Standards Committee (MPSC))

The Committee considered this proposal and requested clarification regarding if this waitlist mortality model includes active and inactive patients. The presenter clarified that the model includes both active and inactive patients. A member also had concerns that this proposal could affect centers listing practices by deterring them from listing higher risk patients, and therefore, limiting this population’s access to transplant. This could also lead to centers listing patients earlier and transplanting them earlier than medically necessary to control outcomes; as patients who are not as sick, at the time of transplant, tend to have better outcomes post-transplant. The presenter stated this issue has been considered by the MPSC and is addressed to some degree in the risk-adjustment. It was also noted that there is potential for the model to be refined based on comments received. Another concern raised was that post-transplant data already limits patient selection criteria and the center’s decision to list or not to list patients. The member was unsure if this proposal will actually help that process.

9. Proposal to Allow Collective Patient and Wait Time Transfers (Operations and Safety Committee (OSC))

The Committee considered this proposal and had some concerns regarding the transferring of patients who are potentially placed in an inactive status. A committee member commented that there needs to be a process in place for both inactive status follow up and patient notification describing what it means to be inactive. Another member commented that patients should be notified/updated on their current status within 90 days of the transfer. There also needs to be a more detailed plan on reporting further progress on the transition, beyond the initial 90 days, for both the governing body and patients involved. The presenter commented this proposal did not specify any new patient notifications. Another concern brought forth was how taking on a collective transfer could affect a center’s pre and post-transplant metrics data. This member felt strongly that provisions need to be put in place to protect these centers who agree to take on these large transfers.

10. Proposal to Reduce the Reporting Requirements for the Deceased Donor Registration Form (Organ Procurement Organization Committee (OPO))

The Committee reviewed and supported the proposal with no questions or concerns.

11. Proposal to Establish a Quality Assessment and Performance Improvement Requirement for Transplant Hospitals and Organ Procurement Organizations (Membership Professional Standards Committee (MPSC))

The Committee reviewed and supported the proposal with no questions or concerns.
12. Clarification of Multi-Organ Policies (Policy Oversight Committee (POC))
   The Committee reviewed and supported the proposal with no questions or concerns.

13. Definition of Organ Transplant and Transplant Date (Policy Oversight Committee (POC))
   The Committee reviewed and supported the proposal with no questions or concerns.

14. Address Requirements Outlined in the HIV Organ Policy Equity Act (Organ Procurement Organization Committee (OPO))
   To assist with an IRB submission, members of the Committee suggested a literature citation list supporting HIV positive transplantation be sent to centers that want to participate in an IRB approved research protocol for HIV positive organs. A member also suggested that an IRB template would be helpful and questioned if NAT testing would be required to run a list. The Committee was informed that the OPTN will not create an IRB template. It will be the center’s responsibility to make sure they meet the submission/participation requirements based on the final research criteria/protocol approved for participation. It was also confirmed that NAT testing will be required.

15. Require Another Match Run Based on Infectious Disease Test Results (Disease Transmission Advisory Committee (DTAC))
   The Committee reviewed the proposal and had the following questions and concerns:
   - Currently, DonorNet® has no means of notifying the primary or backup centers, nor is there a consistent practice or requirement for OPOs to notify centers of a significant change in donor results that resulted in a match re-run. It was requested an alert or indicator be added to DonorNet® that would notify the centers of the following: that the match has been re-run, that a change has occurred, and what that change was. This not only promotes patient safety, but it can also facilitate the reallocation process.
   - A Committee member asked if an infectious disease test comes back positive, after allocation has started, and the first accepting center still wants to continue knowing the test is positive, is there any reason to re-run the match with the positive test result.
   - A Committee member asked whether the backup center(s) should also be offered this option before re-running a list. A potential recipient could run the risk of not showing up on the match re-run due to donor selection criteria.
   - A Committee member asked if the recipient is in a critical state, should they be given the right of first refusal as backups also. The Presenter stated the practice would be to re-execute the list, if new serology results were noted, and backups would be placed off the second list.

16. Clarify Individual Wait Time Transfer Policy and Process (Patient Affairs Committee (PAC))
   Members of the Committee had some confusion about calculating waiting time. Education may be required to clarify this for centers.

17. Collect EVLP Data for Transplant Recipients (Thoracic Transplantation Committee)
   A committee member suggested the TRR help documentation clearly define “N/A” to make sure individuals completing the form understand the questions related to the process.

18. Modify Sterile Internal Vessels Label (Operations and Safety Committee (OSC))
   The Committee agreed that it is important for the vessel labels to indicate the different positive options for HBV testing results.
Other Committee Work

19. Transplant Coordinators Listserv

The objective of this listserv is to facilitate the sharing of information regarding the practice of transplant coordinators. Membership is open to transplant coordinators of OPTN/UNOS approved (or pending approval) transplant providers within the United States. Membership is also open to employees of UNOS, HRSA, and other governmental or governmental contract agencies that participate in the management or oversight of organ transplantation. As of April 8, 2015, there are 387 listserv members with individuals requesting membership daily.

20. Organ Offer Discussion

The Committee discussed the challenges of DonorNet\textsuperscript{®} regarding efficient organ placement. The most common concerns expressed were the misuse of the “provisional yes”, need for effective practices from both transplant coordinators and OPO coordinators, better communication between OPO and transplant center, not being able to upload images to DonorNet\textsuperscript{®}, and not being able to access DonorNet\textsuperscript{®} on all mobile devices. In efforts to begin addressing these concerns, the Committee requested that UNOS IT present its plan for DonorNet\textsuperscript{®} enhancements during one of its monthly meetings and the TCC will assign two representatives that will work with the Liver and Intestine Committee on its Ad Hoc Subcommittee on Increasing Liver Donation and Utilization. Members also agreed there needs to be a UNOS driven, in-person, brainstorming effort to discuss these issues.

21. Educational Work Group

The TCC Education Work Group continues to provide structural and content feedback on OPTN/UNOS educational efforts regarding policy and their impact on practice upon request.

The Work Group plans to work with UNOS Instructional Innovations to develop an educational needs assessment survey that will identify topics and effective educational mediums for the transplant community.

The Work Group reviewed the UNOS Instructional Innovations 2015 instructional plan and thought the MPSC post-transplant outcomes monitoring would require more educational efforts. The Work Group also responded on December 17, 2014 to the Patient Affairs Committee’s (PAC) request to provide feedback on how transplant centers educate candidates about the waiting list. For more information, see the PAC Report to the Board.

Meeting Summaries

The Committee held meetings on the following dates:

- October 15, 2014
- November 19, 2014
- January 21, 2015
- March 5, 2015

Meetings summaries for this Committee are available on the OPTN website at: http://optn.transplant.hrsa.gov/converge/members/committeesDetail.asp?ID=62.