

**OPTN/UNOS Transplant Coordinators Committee
Report to the Board of Directors
November 12-13, 2014
Richmond, VA**

**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 May through September 2014.

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.

The original proposal involved sending letters to patients who had been inactive continuously for one year notifying them of their inactive status, that they would not receive organ offers while inactive and the telephone number of the transplant center. After review by the Executive Committee and Policy Oversight Committee, it was suggested that patients should be notified prior to one year. Thus the proposal was changed to notification of patients continuously inactive at 3 months and one year.

The new proposed policy would have required transplant hospitals to provide written notification to candidates with an inactive waiting list status when the candidate has been inactive for:

- 90 consecutive days
- 365 consecutive days
- Annually, thereafter, for as long as the candidate remains inactive

The notification must include *all* of the following:

- The most recent date they became inactive,
- That the candidate cannot receive organ offers for transplant while inactive, and
- A telephone number at the candidate's transplant center to contact for more information

The Committee reviewed the public comment feedback and the majority of the public comments were not favorable. Common themes from the regional meetings, other OPTN Committees, and the public were that the proposal would cause an increased burden on

transplant centers and it would be difficult for centers to maintain compliance. Other comments requested that the Committee consider alternative notification methods, the data did not support the proposed problem, and educational resources should be provided for transplant center and patients. These themes were discussed by the Committee and its responses are below.

As for the burden concern, most policies create a burden on some level for transplant hospitals and are monitored for compliance. Much of the opposition to this proposed policy has to do with the concept of “burden.” The concept of burden refers to the additional use of personnel and resources that might be needed to comply with the policy, and the financial burden related to additional administrative costs that might be incurred related to mailing letters and monitoring for compliance.

As outlined in the proposal, costs were calculated by looking at recent data over a one year period of time. Individuals that expressed concern about the anticipated burden during the public comment period did not provide center data-driven estimates for these perceived costs the policy would create. Comments also suggested that the change in kidney allocation system (KAS) may impact the inactive waitlist once it is in place. The Committee agreed this was a possibility and would decrease the administrative burden for kidney programs.

Transplant professionals share a both a privilege and an obligation of caring for patients needing organ transplants. This obligation begins when the transplant center starts the transplant evaluation process and agrees to commit time, energy and resources to these patients, if and when, the patients are listed for transplant. This is regardless of whether the patient is listed in an active or inactive status. The current policies do not require centers to notify patients when listed as inactive or placed in an inactive status, does not require any routine follow up of these patients while inactive, and does not assure that the patient understands what it means to be “inactive” on the transplant list.

The current UNetsm programming has the ability to track candidates who have been waiting in an inactive status and is available for centers that do not have computer programs in place to aggressively manage their waitlists (active or inactive). It is the transplant center’s responsibility to assure care for all patients on their waitlist and a patient’s well-being should take precedence over the perceived administrative burden.

Other opposing comments for this proposal focused on the concern of an additional compliance monitoring. CMS, Joint Commission, and OPTN regulations, policies, and obligations exist for the patient’s safety and currently focus mainly on the “active” waitlisted patients; therefore, the population of patients listed as “inactive” might be overlooked. There are no regulatory measures in place to ensure this population’s access to transplant is protected.

This proposal’s intent was to ensure these safeguards exist for a population that is not currently protected under the current system and based on the current OPTN Key Goal of increasing access to transplant by informing candidates on the waiting list with an inactive status that they are not eligible to receive an organ offer, this needs to be changed.

As for the comments that stated the proposal did not support the proposed problem; data in the literature suggest that patients are less likely to be transplanted if inactive and that patients do not understand what it means to have an inactive status. The Committee believes patients would be more proactive in their plan of care if they understood what it means to be inactive and this would increase access to transplant.

After reviewing public comment feedback, the Committee discussed the future of the proposal and voted not to submit it to the Board or develop a guidance document at this time. Next steps will be to partner with the Patient Affairs Committee (PAC) to write a section for inclusion in the *What Every Patient Needs to Know* brochure regarding the inactive waitlist and what it means to be inactive. It will also begin writing effective practices articles for posting to NATCO's newsletter and other transplant professional newsletters/websites to include the OPTN website and TransplantPro. Another suggestion was to survey transplant hospitals on effective waitlist practices. The Committee will also review data to see if the KAS has had any effect on the inactive waitlist at six months and one year after implementation. The Committee will then decide if revisiting the proposal is appropriate.

If the proposal is revisited at a later time, the Committee will consider alternative notification methods as suggested when developing new policy language. The Committee will also consider policy language that describes what is included in the notification, for example, reason for inactivity, steps to be reactivated, and telephone number to transplant hospital.

2. **Tiedi® Help Documentation**

Public Comment: N/A

Board Approval: N/A

The role of this Tiedi Subcommittee is to make recommendations that will improve the accuracy and the completeness of data by reviewing the documentation that exists in the Tiedi help documentation. The group is also working to clarify what data needs to be entered into the forms for accurate/complete data to be collected and provide recommendations on how to educate users.

On July 23, 2014, the Subcommittee met and completed its review of all the fields on the Tiedi data collection forms (TCR, TRR, TRF, PTM, and DDR). In some cases, UNOS staff were able to immediately revise help documentation based on the Committee's recommendations. During this process, they looked at the data collection field, the form, the section on the form, the values allowed for data entry, and the corresponding help documentation or glossary definitions. For each element, they commented on whether or not it was still clinically up-to-date, whether or not the help documentation was actually helpful or even correct, etc. There were many help documentation revisions for clarity and correction as well as some label changes to fields. In addition to reviewing the help documentation, the Subcommittee identified fields that appeared to be either research in nature or no longer applicable, and have suggested those fields be considered for deletion. Also, all currently optional fields will be deleted within the Tiedi® forms with the next OMB update (scheduled for spring 2015). The Subcommittee's questions and suggested revisions to current fields are currently under review by UNOS Research and will be sent to the appropriate committees to review. Recommendations for non-substantial deletions will be made without referring back to committees. Possible educational/training/communication efforts for the transplant community are also being considered.

Committee Projects Pending Implementation

None

Implemented Committee Projects

None

Review of Public Comment Proposals

None

Other Committee Work

3. Disease Transmission Advisory Committee (DTAC) Failure Mode and Effects Analysis (FMEA) Project

The TCC has a representative assigned to the DTAC FMEA project and provides updates to the full Committee on the group's progress. The TCC representative for this project provides feedback on current communication practices and the potential for delays that may negatively impact organ recipients. For more information, see the **DTAC's Report to the Board**.

4. Operations and Safety Committee (OSC) Infectious Disease Verification

The TCC has two representatives assigned to the OSC Infectious Disease Verification Work Group. The representatives for this Work Group provides 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 **Operations and Safety Committee's Report to the Board**.

5. OSC Clarify Requirements for Blood Type Verification

The TCC contributed to the OSC ABO Verification Policy Modifications and Standardization of Documentation project. The TCC representative for this subcommittee provided feedback regarding the potential impact of proposed policy on the entire transplant coordination process. For more information, see the **Operations and Safety Committee's Report to the Board**.

6. OSC Involuntary Waitlist Transfer

The TCC contributed to the OSC Involuntary Waitlist Transfer project. The TCC representative for this project provided the transplant coordinators' perspective on issues, including patient safety issues, related to large volume patient transfers. For more information, see the **Operations and Safety Committee's Report to the Board**.

7. 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 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 September 29, 2014, there are 361 listserv members with individuals requesting membership daily.

8. Organ Offer Discussion

The Committee formed a subcommittee to discuss the challenges of DonorNet® regarding efficient organ placement. The group discussed some of the reasons for the extended amount of time it takes to complete the organ placement process when using DonorNet and is concerned that it can lead to organ wastage. Some of the reasons discussed were increased risk donors, provisional "yes" issue, proper listing practices, and there is not a

system in place for members to discuss DonorNet issues/concerns. The group was informed that UNOS is developing an online DonorNet discussion forum to collect members' issues/concerns and to also share effective practices with others that use the system. The Organ Offer subcommittee has offered to work with UNOS to provide input and feedback on the DonorNet discussion forum. UNOS is currently evaluating possible forum platforms and hope to make a decision by November 2014. The Organ Offer subcommittee will invite UNOS staff to present the DonorNet discussion forum process plan on a conference call in November or December.

9. Scientific Registry of Transplant Recipients (SRTR)

The Committee continues to receive updates on SRTR activities and provides feedback upon request. These updates have included information regarding recent changes to the Program Specific Reports (PSRs), PSR process and timeline modifications, and the transition to Bayesian Methodology.

10. 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.

Meeting Summaries

The Committee held meetings on the following dates:

- July 7, 2014
- September 9, 2014

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