

**OPTN Ad Hoc International Relations Committee
Meeting Minutes
April 18, 2019
Conference Call**

**Kishore Iyer, MBBS, FRCS, FACS, Chair
Barry Friedman, RN, BSN, MBA, CPTC, Vice Chair**

Introduction

The OPTN Ad Hoc International Relations Committee met via teleconference on April 18, 2019 to discuss the following agenda item:

1. Review of draft program questionnaire

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

1. Review of Draft Program Questionnaire

Summary of discussion:

Committee leadership agreed that in evaluating the questionnaire and making several revisions, it was time to move forward with the questionnaire in order to begin collecting additional information about non-US resident transplant activity. The initial set of questionnaires will be focused on the higher volume liver programs. Higher volume programs are defined as having greater than 5% NCNR registrations or deceased donor transplants for a specific organ type and greater than 5 NCNR registrations or deceased donor transplants for a specific organ type during the most recent 3 year period (2016-2018).

UNOS staff stated that if there would not be a statistical analysis done on the data collected, a small sample size would be fine to use. UNOS staff added that the Committee should consider that typically surveys do not have a 100% response rate. If only twelve centers are part of the initial effort, the data would be dependent on the number of responses. The Vice Chair stated that this would be the responsibility of Committee leadership to solicit support for this effort. A member agreed with this and stated that it would be more of a qualitative study and collecting useful information from the transplant centers. The goal is to understand and gain some insight of how these programs have approached and evaluated these candidates. Although challenging, it would be best to start with a small sample size.

Another member stated that survey responsiveness could be dependent on who is contacted about the survey. The member continued asking what policies can be put in place that would help facilitate the global awareness of countries developing their own organ transplant systems. Once the data is understood, a policy position could be recommended to minimize this type of activity.

A member voiced concern on the amount of responses from the questionnaire. It was suggested that it would be easier to have the questionnaire sent electronically. Another member agreed with this and stated that the survey is short and shouldn't take a long time to complete. The member continued that if the survey is mailed, it would likely not be returned.

Another member asked what individuals at the transplant programs would receive the survey. One member clarified that, based on previous discussions, the questionnaire would be sent to both the program directors and transplant administrators, with the recognition that the transplant administrators would be instrumental in completing the questionnaire. The member also suggested that transplant programs should be afforded the opportunity to discuss the

questionnaire with committee leadership. The Vice Chair agreed with this and volunteered to be the point of contact. A member also suggested that an introductory letter from Committee leadership be distributed with the questionnaire. The Committee agreed with this. The Committee members also agreed that a personal phone call from Committee leadership would be beneficial to clarify that this questionnaire is not punitive and that it is intended to provide more information for the Committee regarding non-US resident transplant activity.

Committee leadership asked UNOS staff if there were any changes to the questionnaire that needed to be discussed. UNOS staff clarified that the survey was originally quite long and contained many open-ended questions. There were significant revisions made so that the questionnaire would be easier to complete. UNOS staff continued by explaining the changes made to the survey. There were originally six questions in the “Individual Candidate and Recipient Related Questions” section of the questionnaire. All were deleted except for one question: “Does the country of origin have a transplant center for the organ needed?” UNOS staff asked members if the question should be left as is or combined with a previous question in the survey. The Committee members agreed that the question should be left as is since it is pertinent to the information that is being sought.

A member suggested including the question asking if the candidates sought transplant services in their country of residency. UNOS staff suggested that the order of these two questions be changed so that it would be more streamlined. Members agreed with this suggestion.

UNOS staff stated that the final revisions will be made to the questionnaire with a final review and vote by the committee during its May 7, 2019 teleconference. Internal staff will also discuss any additional steps needed to move the questionnaire forward, including a draft cover letter to explain the questionnaire to participants. UNOS staff also noted that surveys need to be submitted and approved by an internal survey review group.

Committee leadership asked UNOS staff if there was a request or need for the questionnaire to be reviewed by the Board. UNOS staff stated that leadership can be made aware of the status but that it did not require approval by the Executive committee. UNOS leadership has been supportive of the Committee’s questionnaire based on the Committee Chair’s presentation at the last Executive Committee meeting.

There were no further comments or questions. The meeting was adjourned.

Upcoming Meeting

- May 7, 2019 (Teleconference)