

**OPTN/UNOS Ad Hoc International Relations Committee**  
**Meeting Minutes**  
**October 9, 2018**  
**Conference Call**

**Kishore R. Iyer, M.D., Chair**  
**Barry S. Friedman, Vice Chair**

**Introduction**

The Ad Hoc International Relations Committee (AHIRC) met via teleconference on 10/09/2018 to discuss the following agenda item:

1. Draft Voluntary Program Questionnaire

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

**1. Draft Voluntary Program Questionnaire**

Summary of discussion:

The Committee continues to develop a voluntary program questionnaire that will be sent to "higher volume" transplant programs. A higher volume center is defined as meeting both of the following conditions during any single year during the most recent 3 year period (2015-2017):

- Greater than 5% NCNR registrations or deceased donor transplants for a specific organ
- Greater than 5 registrations or deceased donor transplants for a specific organ

The Executive Committee had previously expressed support for the Committee's efforts to reach out to these programs to gather information about their practices. The Committee Chair noted that the Executive Committee did not request to sign off on the questionnaire.

The Committee reviewed and supported the "goal" section of the questionnaire. The Committee also supported the "survey population" section with one minor edit to change "high volume center" to "higher volume center" since the percentages and overall numbers are low.

The Committee next reviewed the "data provided to program" section. UNOS staff noted that the data provided to the programs will include patient and graft survival, median time to transplant, waitlist mortality for kidney, and MELD and PELD score at transplant for liver. UNOS staff also noted that there will be a separate questionnaire for kidney and liver transplant programs.

UNOS Research staff noted that median time to transplant for kidney is difficult to calculate because the waitlists are so long and less than 50% of the candidates receive a transplant. The Committee had previously discussed using data such as the percent transplanted at a specific point in time. The Committee will continue to consider this option.

The Chair suggested looking at the percentage of kidney patients who were transplanted preemptively (i.e. never on dialysis) in each category. There are potential issues with the accuracy and feasibility of getting this data for NCNR candidates but UNOS Research staff agreed to look into this further. The Chair was also concerned that, in the current system, kidney candidates get prioritization based on time on dialysis so an NCNR candidate that started dialysis outside of the U.S. may not be getting credit for that time.

One Committee member commented that the data summarized in a recent publication looked at the higher-volume NCNR centers and patterns of the waiting lists. One of the Committee's

concerns was that even with the small absolute numbers, there were some patterns that suggested there could be regional pockets of influence.

The Committee reviewed the “program specific questions” and a summary of their discussion is provided below:

1. Does your center have a formal process for evaluating and accepting NCNR transplant candidates/recipients? No recommended changes.
2. Does your program or hospital have a written formal philosophy or position regarding evaluation and acceptance of NCNR? The Committee recommended that “formal philosophy or position” be changed to “policy.”
3. What institutional structure governs the hospital? No recommended changes.
4. Do you assess how listing NCNR transplant patients may impact patients within your service area that reside in the U.S.? No recommended changes although one Committee member noted that this question could cause defensiveness from a center and make them feel obliged to say "yes." There was no response to this comment.
5. What is the process at your center for determining citizenship reporting for establishing NCNR - Travel for Transplant and Travel for Other Reasons and who makes the determination? One Committee member suggested this question have multiple choice answers instead of an open-ended response. The Chair suggested the question could be separated into two questions: 1) who determines citizenship with a few answer choices (e.g. data coordinator, transplant surgeon, clinical coordinator, other to specify) and 2) how was that determined with a few answer choices (e.g. passport, birth certificate, travel documents, high school graduation, etc.)
6. Does the program or center have any formal or informal agreements with other countries to provide transplant services to NCNR candidates? One Committee member noted that any center that answers "yes" to this question might be in violation of policy. The Committee agreed to leave this question because it might show if some centers are indifferent to the policies.
7. Does your transplant program have processes to ensure pre-transplant and post-transplant follow-up care for NCNR patients? The Chair expressed concern with this question because the answer choices are only yes and no. The Committee decided the question could have a follow-up question such as asking for the percentage of patients that get lost to follow-up. UNOS Research staff agreed to see if that information could be calculated for NCNR and added to the data table. If not, this can be added as a follow-up question.

The Committee discussed the “individual candidate and recipient related questions.” There was some concern about the title of this section because one candidate could be a candidate and a recipient or they could just be a candidate and never be a recipient. The other concern is some centers have many NCNR candidates and therefore would be asked to fill out this section for multiple candidates and recipients. The Committee members agreed that the questionnaire should not cause undue burden to complete but also agreed that it is important to get an understanding of each patient.

The questions in the individual candidate and recipient-related questions section are:

1. Did the candidate/recipients seek organ transplant services for organ failure in their home country or country of citizenship? The Chair felt the value of this particular question is somewhat limited. He suggested was to break this into separate questions about candidates and recipients and then provide four ranges of percentages. The

information would then be reported out on a percentage level as a summary. The Committee agreed with this approach.

2. Does the country of origin have a transplant center for the organ needed? The Committee agreed that this question could also take the same percentage approach as the previous question. The data could even be evaluated after the fact if the country of origin for the relevant center could be obtained. The Committee members noted that Saudi Arabia and Kuwait are the two leading countries for kidney and liver NCNRs despite the fact that both countries have transplant programs. The Chair stated that from informal conversations, those transplant programs do not have adequate services to meet all the population needs. However, the same case could be made for services in the US. One Committee member agreed it is important to know the drive for self-sufficiency in these countries and what is available to patients.

The Chair asked whether a question should ask for the country of origin. UNOS Research staff could obtain the country of origin and determine whether they have a transplant center. The Committee agreed it would be relevant to know and fair to ask how many NCNRs had access to transplant centers in their home countries. The Committee agreed that this question will be changed to ask whether the US centers ask if there is a transplant center for the organ needed within their home country. The Chair also asked whether other countries with transplant activity publicly report that information. Another Committee member confirmed that transplant data is publicly reported in Saudi Arabia through the Saudi Council on Organ Transplantation. It might be possible to independently verify for each of the countries in the survey how many transplants they are performing.

3. Why did the candidates/recipients travel to the U.S. to receive an organ transplant? The Committee discussed how this question has an open-ended response. There was a recommendation to provide a list of potential answers such as no transplant program in country of residence, seeking best possible medical care, other reasons, etc. If the answer is "other reasons" then also include some potential answers for that response.

The Committee discussed whether transplant centers would be willing to share this information for each candidate. The Chair suggested the question be changed to ask them to arrange given answers in order of importance to help identify why NCNR candidates can't get transplanted in their country of residence. The Committee agreed that this would make the question easier to answer and make it more likely that centers would complete the survey. The wording of the question could be objective, for example instead of "rank the reasons in order of importance why NCNR candidates travel to your center to receive a transplant," use the word "frequency."

4. Do you evaluate the resources available to support NCNR candidates before and after transplant? No recommended changes.
5. What was the indication (diagnosis) for transplant for each candidate? The Chair noted the concern about answering this question for each candidate. UNOS Research staff noted that this information might be available from the registration forms and agreed to look into this. The Committee agreed to leave this question in the questionnaire if the information cannot be obtained internally. This might provide some information about whether centers are transplanting NCNR candidates for metabolic diseases that allow them to show up higher on the list, most notably for pediatric candidates.
6. What is the payer source? The Committee agreed to propose answers based on how this information is collected on the registration forms.

Next steps:

UNOS staff will make the edits to the questionnaire and distribute the revised version to Committee leadership.