

OPTN/UNOS Ad Hoc International Relations Committee
Meeting Minutes
February 21, 2018
Conference Call

Susan Gunderson, MHA, Chair
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Introduction

The Ad Hoc International Relations Committee met via teleconference on February 21, 2018, to discuss the following agenda items:

1. Review draft program questionnaire
2. Non-US resident living donor data request

The Committee chair noted a publication that went out for early release in December 2017. The publication focuses on data similar to what the Committee has been evaluating over the past few years.

The Committee members were reminded about the portal site which contains important information for the committee. This includes all current and past meeting information, annual reports, and the committee roster. The liaison provided a demonstration of the portal site and how to navigate to the various sections to find information.

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

1. Review draft program questionnaire

The Committee has been discussing over the past year the need to develop a voluntary questionnaire to help better understand the practices and activities of transplant centers in the U.S. that have a higher volume of non-citizen, non-resident (NCNR) transplant activity.

Summary of Discussion:

The goal of the questionnaire is to get a better understanding of the NCNR transplant activity at specific transplant programs within the country. There was interest in looking at programs with higher volume NCNR transplant candidate listing and transplant activity. For the initial phase, the Committee has discussed using three years' worth of data and identifying programs that have greater than 5% NCNR registrations for deceased donor transplants in any one of those three years. Additionally, the Committee looked at programs that had at least five registrations or deceased donor transplants over the three-year period. All other programs with a particularly low overall volume would be excluded from the analysis. Finally, the initial inquiry would focus on kidney and liver programs because they have the highest frequency of activity.

The Committee had previously discussed whether or not to include living donor transplant programs with higher volumes. There was agreement that eventually living donor programs should be part of the inquiries but further data analysis is needed first.

The Committee reviewed the changes made to the questionnaire based on feedback during the previous conference call. The Committee discussed providing data to each program which could include patient and graft survival, median time to transplant, MELD/PELD at transplant for liver recipients, and total number of NCNR transplant.

UNOS Research staff asked a question about the patient and graft survival data. The numbers are going to be very low and it probably wouldn't be relevant to calculate a Kaplan-Meier

survival rate on the NCNR transplants. Since the number of transplants will be small there was concern about comparing it to the other columns without a risk adjustment. With such low volumes, it was recommended that the Committee could just ask, out of the number of transplants, how many patients had graft failure or death within the cohort period? There was a suggestion that the Committee should start by looking at the raw data in terms of survival without trying to do a comparison.

The Committee chair noted that the Committee should be able to get the data first before sending it to the transplant centers. The Committee will need to decide on the timeframe and the outcome they would be looking at before an analysis could be done. The Committee had talked about the cohort being a three-year time period, and we currently have data for four years. The suggestion was that the data include both one-year and three-year survival. The data will be brought back to the Committee for additional discussion, focusing on kidney and liver first.

Program Specific Questions

The following question was added: What institutional structure governs the hospital? Public (state/county funded), private (for profit, not for profit) Other? How does the institutional structure contribute to the program's position?

One Committee member raised an issue with the following question: What is the process at your center for determining citizenship reporting for establishing NCNR-TFT and TFO, and who makes the determination? The member noted that one of the pushbacks from transplant centers and OPOs has been that they ask or document the question, particularly for donors. UNOS staff noted that for donors, the centers can respond with unknown, but for candidates and recipients, a response to the citizenship question is required on the candidate registration forms.

Individual Candidate and Recipient Questions

The following questions were added:

- Does the country of origin have a transplant center for the organ needed? This question was added to assess whether there was any capability for the patient to have been transplanted in their home country.
- What is the payer source: humanitarian (charity), self-funded, state sponsored, or other? This is added as an effort to gain an understanding of how the transplants are being financed. There was a suggestion to make the payer source consistent with the information collected on the candidate registration forms.

The Committee chair asked if the Committee supported bringing the questionnaire to the leadership of the Executive Committee. This should not require Executive Committee approval, instead it is more of an endorsement to pilot the form. The Committee would then be able to send the questionnaire to the identified transplant programs once the data has been added. There was a recommendation that the questionnaires be sent directly to the administrative directors and copying the medical and surgical directors. The rationale for this was that the questions are more administrative than clinical. There was some discussion about whether it would be beneficial to also include the CEO of the hospital as well. The Committee chair noted that there are about 35 kidney and liver programs identified as high volume, however, the Committee could identify 2 or 3 programs from the kidney and liver programs to test the questionnaire.

There was an additional suggestion to engage with the Living Donor Committee, perhaps at the next board meeting, about whether they think more information on living donors in the international group would be helpful.

The following question will be added: How many NCNR patients who traveled to the US for a living donor transplant ended up receiving a deceased donor transplant?

Next steps:

- Identify 2 or 3 programs for kidney and liver to be pilot sites.
- Add data to the questionnaire as discussed earlier.
- Send the questionnaire to the Executive Committee leadership for review.
- Phone calls to give the programs a heads up about the questionnaire.
- Send the questionnaire to the administrative, medical, and surgical directors.

2. Non-US resident living donor data request

The Committee chair presented the following list of living donor data that could be part of a data request for both kidney and liver:

1. Recipient and donor citizenship and residency for living donor transplants performed during 2013-2016 - by year and total

Expanded to include a breakdown of:

- LRRT (living related and spousal renal transplant) vs. LURT (living unrelated renal transplant)
- LRLT (living related and spousal liver transplant) vs. LULT (living unrelated liver transplant) (reported as Table 5 in the 2016 Report of Non-US Resident Transplant Activity)

2. Recipient and donor citizenship and residency for living donor kidney transplants performed – by Transplant Center, by year, total 2013-2016

Expanded to include a breakdown of:

- LRRT (living related and spousal renal transplant) vs. LURT (living unrelated renal transplant)
- LRLT (living related and spousal liver transplant) vs. LULT (living unrelated liver transplant) (expanded Table 8 and 15 from 2016 Report of Non-US Resident Transplant Activity)

3. Living donor and recipient transplants by organ and recipient country – Kidney and Liver – 2016

Expanded to include a breakdown of:

- LRRT (living related and spousal renal transplant) vs. LURT (living unrelated renal transplant)
- LRLT (living related and spousal liver transplant) vs. LULT (living unrelated liver transplant)

This data will allow the Committee to analyze the NCNR living donor transplant data

Next step:

UNOS Research staff will draft a data request form and submit it to HRSA for approval. This data will be presented during a future conference call.

Upcoming Meeting

- March 12, 2018 (Conference Call)