

OPTN Ad Hoc International Relations Committee

Meeting Summary

September 8, 2020

Conference Call

Barry Friedman, RN, BSN, MBA, CPTC, Chair

Pramod Bonde, MD, Vice Chair

Introduction

The Ad Hoc International Relations Committee (AHIRC) met via Citrix GoToMeeting teleconference on 09/08/2020 to discuss the following agenda items:

1. AHIRC Information Request Results
2. Update on Additional Data Reports
3. Continuous Distribution Community Outreach
4. Next Steps

The following is a summary of AHIRC's discussions.

1. AHIRC Information Request Results

The Committee reviewed the results of the Information Request. The Information Request was open from June 22, 2020 through July 18, 2020 and had the following goals:

- Understand transplant center policies and practices, regarding acceptance of non-US citizen/non-resident (NCNR) as transplant patients
- Increase understanding of NCNR candidates
- Increase transparency and trust
- Improve NCNR transplant policy

The Information Request was sent to 75 transplant programs and had a 44% response rate.

Data summary:

The following are key takeaways from the Information Request:

- Just over half of the programs have a formal process to accept NCNR candidates
- 52% of programs surveyed have an impact assessment for how NCNR candidates affect their area of service
- Only a few number of NCNR candidates have a transplant program in their country of origin

Summary of discussion:

A member expressed concern regarding the designation of all the NCNR candidates that have been transplanted in California and how this designation might not be addressed accurately by some of the responding centers. The member believes the classification might be problematic because in these instances the candidates should be classified as non-citizen resident.

The Committee Chair mentioned that there was one center that made corrections to the categorization of their NCNR patients after realizing that "non-resident" in NCNR refers to primary place of residence.

Members agreed that the following are two opportunities for education in regards to the Information Request results:

- Education to help transplant centers better understand what it means to designate a patient as NCNR and how this data is being used
- Education to help patients better understand the requests coming from transplant centers performing NCNR transplants, such as follow-up

2. Update on Additional Data Reports

United Network for Organ Sharing (UNOS) Research staff presented results on the following additional data requests:

- Waiting time for NCNR candidates vs. US residents
- The current report only shows countries of origin for 2019. Provide more summarization on countries of origin
- Post-transplant follow-up for NCNR living donor transplant recipients

Summary of discussion:

A member inquired about how many deceased donor transplants occur each year from non-citizens and how many living donor transplants occur from non-citizens. UNOS Research staff explained that, in 2019, there were 615 NCNR newly added kidney registrations and 265 NCNR kidney transplants. In 2019, there were a total of 436 NCNR deceased donor transplants and 78 NCNR living donor transplants for all organs.

A member questioned whether the majority of these transplants are being done in California. UNOS Research staff explained that that's correct for Mexican NCNR candidates; however, overall, the majority of these transplants are occurring in California, New York, and Chicago.

A member inquired if there's data collected on the number of NCNRs that are deceased organ donors in order to see if there's an even exchange between NCNR donors and US citizen donors. Members emphasized that it's important to understand how many NCNR living and deceased donors there are in the US. It was mentioned that the AHIRC Annual Report hasn't historically looked at the number of non-citizen deceased donors.

The following questions were raised in regards to living donor recipient compliance:

- Is there a breakdown of how many living donors were citizens versus non-citizens?
 - This data is just looking at recipients of living donor transplants and measuring their compliance.
- Is this data inferring that there's non-adherence from the recipient side?
 - There's less adherence from NCNRs than from US citizens, but we don't know why that is – these NCNR recipients could be receiving follow-up care in their home country and not communicating to the center that performed the transplant.
- Is there no way to tell whether these NCNR recipients stayed in the US or moved back to their country?
 - Correct, there's little data from those that get a deceased donor transplant with the kidney – a good majority of them become citizens or residents by the time of the second transplant.
 - Aside from getting a second transplant, there's no information as to why NCNR living donor recipients aren't getting follow-up care.

A member questioned if the financial burden of NCNR transplants has been assessed. UNOS staff weren't aware of this being looked at and it was mentioned that this wasn't in the scope of the Information Request. A member stated that, traditionally, this isn't something that the OPTN analyzes but, usually, the individual center performing the NCNR transplants.

3. Continuous Distribution Community Outreach

UNOS staff reviewed ways Committee members could remain engaged, such as the Continuous Distribution community exercise and attending regional meetings.

Summary of discussion:

No discussion.

4. Next Steps

The Committee will continue to discuss the results of the Information Request and produce educational recommendations to present to the Executive Committee in December.

Upcoming Meeting

- TBD

Attendance

- **Committee Members**
 - Barry Friedman
 - Pramod Bonde
 - Howard Nathan
 - Min Zhou
 - Prakash Rao
 - Samy Riad
 - Peter Stock
 - Sylvia Gonzalez
- **HRSA Representatives**
 - Jim Bowman
 - Vanessa Arriola
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Alice Toll
 - Craig Connors
 - Katrina Gauntt
 - Laura Cartwright
 - Leah Slife
 - Matthew Prentice
 - Pete Sokol
 - Rebecca Brookman
 - Robert Hunter