

OPTN Ad Hoc International Relations Committee

May 27, 2021

Conference Call

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

Pramod Bonde, MD, Vice Chair

Introduction

The OPTN Ad Hoc International Relations Committee (the Committee) met via Citrix GoToMeeting teleconference on 05/27/2021 to discuss the following agenda items:

1. Discussion: Citizenship Status Guidance Document
2. Policy Oversight Committee Update

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

1. Discussion: Citizenship Status Guidance Document

The Committee discussed their current project, *Guidance for Data Collection Regarding Classification of Citizenship Status*.

Summary of discussion:

The Chair stated that the citizenship status data element is collected for OPTN use, and does not identify immigration status. The Committee agreed to address how the data collected from the citizenship status element is utilized, in order to create trust and transparency. A member added that while they agree to include this, it may not resolve the hesitation that candidates and donors have in reporting their citizenship status.

The Chair suggested the guidance document address the former OPTN policy that allowed the Committee to review transplant programs who reported more than 5% non-U.S. citizen/non-U.S. resident (NCNR) transplant activity.

The Committee reviewed the UNet Help Documentation for the citizenship status data element. A member stated there is a lot of confusion regarding the term "resident." Another member stated that for this OPTN data collection element, a green card is not needed to be categorized as a U.S. resident. The member added that undocumented immigrants are also categorized as U.S. residents due to the fact that they are residing within the U.S. Staff clarified that regardless of a patient's legal status, if the individual lives in the U.S., they are to be categorized as a non-U.S. citizen/U.S. resident. Staff explained the difference between non-U.S. citizen/U.S. resident and non-U.S. citizen/non-U.S. resident, who travel to the U.S. for reasons other than transplant, is that the latter is used to categorized individuals who do not live in the U.S. but are traveling.

A member suggested clarifying the definition to include a residency time period for when a non-U.S. citizen would be considered a U.S. resident. Another member stated that designating a time period would not be helpful because once a person moves, they are a resident of the new location regardless of the period of time they have lived there. The member suggested clarifying the definition to include that categorization of a non-U.S. citizen/U.S. resident require legal documentation. Staff clarified that, historically, the Committee intentionally did not address legal status because they did not seek to collect

legal status on OPTN forms. The Chair requested more information about what resource was used as a basis for these data definitions.

A member asked what type of source documentation is used for reporting citizenship status. Another member responded that their program's standard is to reference the social worker consultation, which contains self-reported information from the patient. The member added that some programs use physician referral, family, or legal documentation.

Another member stated that lack of standard, verified source documentation and unclear citizenship status data definitions results in a transplant program's inability to report on follow-up data. The member stated that reasons for the low rates of follow-up for NCNR recipients and donors are similar to those of U.S. citizens, except exacerbated due to minimal mechanisms to receive data from other countries. The Chair stated that transplant programs need to work with recipients and donors at the time of listing to ensure there is an engaged caregiver in their home country in order to receive data for follow-up form submission.

A member stated there is difficulty in following up with living donors who have traveled to the U.S. for transplant. The Chair agreed and stated that transplant program staff should explain the importance of follow-up care during the pre-transplantation period. The Chair added that communication between the transplant coordinator and the caregiver in the patient's home country should be established prior to transplant. The Chair stated there is no guarantee that a patient will return to U.S. for any post-transplant care, but transplant programs should have these conversations prior to engaging in transplant activity with NCNR patients to ensure arrangements are made for follow-up prior to transplant. A member stated that transplant programs that engage in transplant activity with NCNR patients should have processes in place to ensure a certain level of follow-up data collection.

Another member stated that financial status and loss of insurance is a factor that results in low follow-up rates of NCNR patients. Another member mentioned that loss of insurance does not prohibit a transplant program from contacting the patient, but it might affect a patient's ability to come in for medical care.

Next steps:

The Committee will continue to draft the guidance document. A final guidance document will be compiled, and sent to the members for review. The Committee will vote on the final guidance document during their next meeting on June 24, 2021.

2. Policy Oversight Committee Update

The Committee received an updated on the work of the OPTN Policy Oversight Committee.

Summary of discussion:

There were no questions or comments.

Upcoming Meetings

- June 24, 2021 (teleconference)
- July 22, 2021 (teleconference)

Attendance

- **Committee Members**
 - Barry Friedman
 - Min Zhou
 - Peter Stock
 - Prakash Rao
 - Sylvia Villalon
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
 - Vanessa Arriola
- **UNOS Staff**
 - Courtney Jett
 - Jen Wainright
 - Meghan McDermott
 - Robert Hunter
 - Savannah Holmes
 - Supraja Malladi
- **Other Attendees**
 - Nancy Long
 - Sarah Schultz