

**OPTN Data Advisory Committee  
Meeting Summary  
November 9, 2020 3:00 PM EST  
Conference Call**

**Rachel Patzer, Ph.D., Chair  
Sumit Mohan, M.D., M.P.H., Vice Chair**

## **Introduction**

The Data Advisory Committee (DAC) met via Citrix GoToMeeting teleconference on 11/09/2020 to discuss the following agenda items:

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

1. Annual Review of Data Review Report & Data Quality Report

### **1. Annual Review of Data Review Report & Data Quality Report**

The DAC reviewed their annual Data Review Report & Data Quality Report. The annual report includes:

- Recommendations for Board of Directors action on additions and deletions of the data elements collected by the OPTN
- Recommendations to improve completeness and accuracy of data collected
- Recommendations to enhance the official OPTN data with elements from other data sources
- Any other recommendations to improve collection of official OPTN data

The Chair will present these reports to the Board of Directors in December 2020.

#### Summary of discussion:

After reviewing the number and types of changes to the peripheral vascular disease (PVD) field on the kidney TCR, a member expressed support to clarify the definition for that element.

Another member stated the data quality report should give more detail regarding the regions with the highest forms in amnesty. The Chair agreed that further stratifications should be analyzed to understand the situation. UNOS staff responded that the Research Department is beginning to analyze the amnesty data more in depth. UNOS staff added that the Executive Committee has received the regional data for forms in amnesty.

A member expressed interest in more data regarding living donors being included in the data quality report, specifically the results of the living donor follow-up (LDF) form related to complications, reoperation, etc. UNOS staff responded that the OPTN Living Donor Committee reviews this data but will note to include this type of data in future data quality reports. UNOS staff added that as part of the review of existing data process, the collection of living donor data will be reviewed. SRTR staff stated that there is interest in convening the DAC and the Living Donor Committee to discuss data collection regarding living donors. SRTR staff is interested in ensuring that appropriate data is collected during the correct time frames. SRTR staff stated that there are duplicate data elements collected between their registry and OPTN data, as well as outdated data elements that need to be addressed. SRTR staff stated

that the objective would involve reviewing the living donor registration (LDR) and LDF forms in order to hone in on essential data that allows for analyzing outcomes for living donors.

A member asked for an update about amnesty status. UNOS staff stated that the Executive Committee requested for the Research Department to evaluate forms in amnesty by center, as well as evaluate data points most necessary for monitoring and ongoing analyses. UNOS staff stated that the Executive Committee will meet December 6, 2020 to discuss these analyses. UNOS staff added that the Executive Committee will send a proposal to the Board of Directors stating that amnesty will stay in effect until the Executive Committee finds it is no longer needed. UNOS staff stated that the Board of Directors will vote on this on December 7, 2020. UNOS staff stated this would not require retrospective data entry at this time. UNOS staff stated that reports are being created and will be communicated to programs so that the programs can view the amount of forms in amnesty status. UNOS staff added that the report will have a list of forms in amnesty status so that programs can easily enter missing data if it is available.

### **Upcoming Meetings**

- December 14, 2020 (teleconference)
- January 11, 2020 (teleconference)

## Attendance

- **Committee Members**
  - Anna Mello
  - Benjamin Schleich
  - Colleen O'Donnell Flores
  - Daniel Stanton
  - Farhan Zafar
  - Kristine Browning
  - Lauren Kearns
  - Macey Henderson
  - Melissa McQueen
  - Rachel Patzer
  - Sandy Feng
- **HRSA Representatives**
  - Adriana Martinez
  - Chris McLaughlin
- **SRTR Staff**
  - Bertram Kasiske
  - Michael Conboy
- **UNOS Staff**
  - Adel Husayni
  - Brooke Chenault
  - Kim Uccellini
  - Lauren Mauk
  - Matthew Prentice
  - Meghan McDermott
  - Pete Sokol
  - Randall Fenderson
  - Sarah Taranto