

**OPTN Data Advisory Committee  
Meeting Summary  
November 18, 2019  
Conference Call**

**Sandy Feng, MD, PhD, Chair  
Rachel Patzer, PhD, MPH, Vice Chair**

## **Introduction**

The OPTN Data Advisory Committee (DAC) met via teleconference on 11/18/2019 to discuss the following agenda items:

1. Public Comment Proposal Update
2. Data-Related HRSA deliverable/Board Report Previews
3. Vascularized Composite Allograft (VCA) Data Collection Projects Update
4. Minority Affairs Committee (MAC) Project to Collect Socio-Economic Status (SES) Data

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

### **1. Public Comment Proposal Update**

The public comment period closed on October 2, 2019. The DAC's proposal to modify data submission policies is slated to go to the OPTN Board of Directors (BOD) for consideration at their December meeting.

#### Summary of discussion:

The DAC heard an update on the progress of the public comment proposal. The DAC reviewed the public comment feedback on the proposal. The DAC discussed the feedback submitted by the American Society of Transplant Surgeons (ASTS). The ASTS noted concern that the proposal would increase administrative burden for transplant programs. The DAC reviewed information on changes made to deceased donor registration (DDR) form fields from 2018. The data supported the DAC's decision to extend the submission deadlines.

The DAC then discussed the Board Policy Group's (BPG) review of the proposal. The BPG voted unanimously to recommend that the BOD approve the proposal and to place the proposal on the consent agenda. The DAC reiterated the importance of monitoring data changes after the submission deadlines at transplant programs, organ procurement organizations (OPOs), and histocompatibility labs.

#### Next steps:

The DAC's proposal will be considered by the BOD at their December meeting.

### **2. Data-Related HRSA deliverable/Board Report Previews**

Besides the policy proposal described above, the DAC Chair will also be presenting a report on behalf of the DAC at the BOD meeting in December. The report will include information on committee business, data review activities and data quality. The report is an OPTN contract deliverable. The DAC received a preview of the report.

Summary of discussion:

The DAC Chair provided some feedback on how the data quality information is displayed in the presentation. The DAC had no other feedback.

Next steps:

The slides will be updated based on the feedback provided. The DAC Chair will present the report to the BOD in December.

**3. Vascularized Composite Allograft (VCA) Data Collection Projects Update**

The DAC previously heard presentations on two upcoming VCA Committee projects – one to update the transplant recipient registration (TRR) and transplant recipient follow-up (TRF) forms for VCA candidates and one to collect data on children born to uterine transplant recipients. The DAC heard an update on the two VCA projects.

Summary of discussion:

The VCA Committee recently met and voted on the proposed changes to the TRR and TRF. The DAC were informed which data elements are being proposed to be added and deleted from these forms. The VCA Committee also decided that they are going to pursue a request for feedback document on collecting data on children born to uterus transplant recipients during the upcoming public comment cycle. A DAC member asked what the VCA Committee hopes to measure or study by collecting data on children born to uterus transplant recipients. The DAC also asked who, exactly, they will be soliciting input from. The DAC noted that it is important to get a broad perspective on this topic as the field is still emerging.

Next steps:

The DAC will continue to collaborate with the VCA Committee on the two proposed projects.

**4. Minority Affairs Committee (MAC) Project to Collect Socio-Economic Status (SES) Data**

The DAC previously heard a presentation on the MAC proposal to collect SES data on transplant candidates. The MAC is proposing adding household size and household income fields to the transplant candidate registration (TCR) form.

Summary of discussion:

The MAC Chair provided an update on the project to collect more granular SES data on transplant candidates. The project is slated to go out for public comment in January. The MAC Chair provided mock-ups of the fields in the system. The MAC Chair provided detailed rationale for why the proposed fields should be added and how the elements will be collected. The MAC Chair responded to the concerns raised by the DAC during the previous presentation.

The DAC Chair asked if the fields would be mandatory. The MAC Chair noted that this is a future decision point for the MAC and they are seeking feedback on this. The MAC Chair noted that the MAC would like the fields to be mandatory but stated that it may be better to start with not requiring the fields. DAC members noted that if the fields are not required, then the data might not be widely reported, which defeats the purpose of the proposal.

Next steps:

The MAC will sponsor a public comment proposal starting in January.

### **Upcoming Meetings**

- December 9, 2019
- January 13, 2020