

**OPTN Data Advisory Committee  
Meeting Summary  
December 9, 2019  
Conference Call**

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## **Introduction**

The OPTN Data Advisory Committee (DAC) met via teleconference on 12/09/2019 to discuss the following agenda items:

1. OPTN Board of Directors Meeting Debrief
2. Q1 2020 Data Definition Clarification Review
3. Removing Health Identification Number (HIC) from OPTN TIEDI® Forms
4. Potential New Data Project: Review of OPTN Lung Data Collection
5. Update: New Data Collection - Kidney Medical Urgency

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

### **1. OPTN Board of Directors Meeting Debrief**

The OPTN Board of Directors (the Board) recently held their December 2019 meeting. The Board discussed and approved the DAC policy proposal to modify data submission policies.

#### Summary of discussion:

The DAC heard a recap of the Board's discussion of the proposal to modify data submission policies. Almost all of the comments made at the Board meeting were supportive of the proposal, with some comments noting that data collection is already a large burden for transplant programs. Other comments were that it is critical to employ technology to reduce human efforts and stressing the importance of data quality and implementation timelines. Next steps for the project include working with other committees to identify best practices for efficient and effective data processes and identifying DAC's role during the policy's implementation.

#### Next steps:

The DAC will remain informed as the project moves into the implementation phase.

### **2. Q1 2020 Data Definition Clarification Review**

The DAC considered three data definitions as part of their first quarter data definition review.

#### Summary of discussion:

The DAC endorsed all three data definitions with no changes.

#### Next steps:

The updated definitions will be published for the transplant community.

### **3. Removing Health Identification Number (HIC) from OPTN TIEDI® Forms**

The HIC is an optional field on a number of data collection instruments in TIEDI®. The Centers for Medicare and Medicaid Services (CMS) has recently replaced it with a Medicare Beneficiary ID (MBI), effective January 2020. The DAC was asked to endorse the removal of the HIC from TIEDI® forms.

#### Summary of discussion:

DAC members asked if the OPTN would now collect the MBI. The DAC was informed that the OPTN would not start collecting the MBI, as it is not necessary.

The DAC endorsed removing the HIC number from TIEDI® data collection instruments.

#### Next steps:

The OPTN will remove the HIC from all TIEDI® data collection instruments.

### **4. Potential New Data Project: Review of OPTN Lung Data Collection**

The DAC received an overview of a proposed project to review OPTN lung data collection.

#### Summary of discussion:

The Lung Subcommittee of the OPTN Thoracic Committee has identified the need to revise the lung allocation score (LAS) after their work on continuous distribution is completed. The Lung Subcommittee intends to initiate collection of potential new data elements needed in a revised LAS score as soon as possible.

The Lung Subcommittee proposed working with DAC to review existing lung-specific data elements for modification or elimination and considering proposed new lung-specific data elements for inclusion in a future LAS revision. The DAC would review the data elements as part of the OPTN's comprehensive data collection effort. The project would be sponsored by DAC but the Lung Subcommittee would serve as clinical subject matter experts.

DAC members had no additional questions.

#### Next steps:

The DAC will remain informed about the status of the project.

### **5. Update: New Data Collection - Kidney Medical Urgency**

The DAC previously received a presentation about potential new data collection as part of the kidney medical urgency policy proposal. The DAC received an update on the proposed new data collection prior to public comment.

#### Summary of discussion:

The DAC was reminded of the problem the proposal intends to address and the proposed solution. The DAC reviewed the proposed definitions for the new data elements – loss of dialysis access and imminent loss of dialysis access. The DAC also considered how the new data collection aligns with the OPTN Data Vision Statement and the OPTN Data Collection Principles.

A DAC member asked how the proposed solution would be monitored, including how many offers are turned down for medically urgent candidates. A DAC member noted that the proposed solution is similar to what most donation service areas (DSAs) are already doing for medically urgent candidates so the data is already being collected. A DAC member reiterated the need to monitor who is being given a medical urgency exception and what their outcome is.

The DAC endorsed the work of the Kidney Committee to collect new data as part of the medical urgency proposal.

Next steps:

The proposal will be posted for public comment starting in January 2020.

**Upcoming Meetings**

- January 13, 2020
- February 10, 2020