

**OPTN Data Advisory Committee  
Meeting Minutes  
June 24, 2019  
Conference Call**

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

**Introduction**

The Data Advisory Committee (DAC) met via Citrix GoTo teleconference on 06/24/2019 to discuss the following agenda items:

1. Modify Data Submission Policies
2. Data Governance – Quarterly Update of Data Definitions

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

**1. Modify Data Submission Policies**

The Committee reviewed the proposed public comment questions, and they suggested revisions. The draft questions were:

- What are the most common reasons your organization changes data values after they have been officially submitted?
- What circumstances or conditions prevent your organization from submitting accurate data within the established timeframes?
- In addition to what is currently available, what data quality-related resources or electronic tools would help your organization ensure data are submitted accurately and within the established timeframes?
- What is the appropriate leadership position within your member organization to approve changing data values after they are officially submitted?

A Committee member asked if the response fields associated with the questions appear on the OPTN website as open text or drop-down fields. The member followed-up that when respondents are prompted, like through drop-down fields, their responses may be more thoughtful. UNOS staff replied that they appear as open text fields. Another Committee member stated that the intent is to drive respondents to hone in on the questions the Committee has about what the issues may be with the policy. Because we’re trying to get respondents to identify their specific issues with the policy, it is hard to have a drop-down. The member stated support for the questions presented, but recommended making the questions less wordy.

Another Committee member asked what the purpose is of the third bulleted question and what types of answers we are expecting.

UNOS staff said that the purpose is to elicit anything that wasn’t mentioned in the paper (what did we not identify in the proposal).

**2. Data Governance – Quarterly Update of Data Definitions**

UNOS staff discussed the data definitions shown in the following table with the Committee members. Members were asked for their feedback and whether or not they endorse the proposed changes. The table also includes the Members endorsement decision, as well as any action items that were identified.

Item #	Data Element	Endorsed by DAC	Action Items (Changes that reflects in the Online Help Documentation of UNET)	Logged for DAC Enhancement (Changes to IT such as Label / Programming or Policy Changes)
1	Cigarette Use (>20 pack years) - Ever	Yes	<ul style="list-style-type: none"> <li>• Data definition clarification to other forms that is related to the data element. This will be an item for 2019-Q4 Data Definition process.</li> <li>• Reach out to Thoracic Committee for the issue of Vaping, e-cigarette, etc. in order to be more relative to the current times.</li> </ul>	<p>Yes</p> <p><b>Possible label &amp; programming change:</b> additional fields with regards to vaping, e-cigarette, tobacco, etc.</p>
2	Candidate/Recipient Gender	Yes	No changes in the definition.	No
3	Total Pancreas Preservation Time	Yes	No changes in the definition.	No
4	Total Organ Preservation Time from Cross Clamp to In Situ Reperfusion	Yes	No changes in the definition.	No
5	CMV Total	Yes	<p>Definition Modification (<i>in blue font</i>) :</p> <p>Select the result of the test (Positive, Negative, Not Done, UNK/Cannot Disclose). <b>Note:</b> CMV total is a combination test. It checks the total result instead of the individual <i>components</i>. To further determine whether the IgG or IgM is positive, tests should be run <i>separately</i>.</p>	No

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6	EBV Total	Yes	<p>Definition Modification (<i>in blue font</i>) :</p> <p>Select the result of the test (Positive, Negative, Not Done, UNK/Cannot Disclose). <b>Note:</b> CMV total is a combination test. It checks the total result instead of the individual <i>components</i>. To further determine whether the IgG or IgM is positive, tests should be run <i>separately</i>.</p>	No
7	Coronary Artery Disease	Yes	<p>Definition Modification (<i>in blue font</i>) :</p> <p><b>Coronary Artery Disease:</b> If the recipient has been diagnosed with coronary artery disease <i>in a transplanted heart</i>, select <b>Yes</b>. If not, select <b>No</b>. If unknown, select <b>UNK</b>. This field is required.</p>	No
8	Total Ischemic Time - Intestine	Yes	No changes in the definition.	No
9	Acute Rejection	Yes	No changes in the definition.	<p>Yes</p> <p><b>Possible Label change:</b></p> <p>TRF</p> <p>Did patient have any <i>new</i> acute rejection episodes <i>since</i> the follow-up period</p>

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<b>10</b>	Core Cooling	Yes	No changes in the definition.	<p>Yes</p> <p><b>Possible Label Change:</b></p> <p>Instead 'Core Cooling', use 'cold perfusion initiated'.</p> <p>Intention of the change is to harmonize with the brain-dead donors and accommodate hypothermia protocols that are only happening on brain-dead donors.</p>
<b>11</b>	Date of Discharge	No	<p>DAC is endorsing the TransQIP definition.</p> <p>Proposed definition by DAC : When is the patient discharged from the acute care hospital.</p> <p>The definition still need more review within the UNOS core team. This will be included in the 2019-Q4 data definition process.</p>	<p>Yes</p> <p><b>Possible label &amp; programming change:</b></p> <p>Proposed if we need to collect the data that pertains to where patients were discharged. Identify if patients were discharged to home, to a facility that is not an acute hospitalization.</p>

**Upcoming Meeting(s)**

- July 8, 2019