

**OPTN/UNOS Data Advisory Committee  
Meeting Minutes  
November 8, 2017  
Conference Call**

**Maryl Johnson, MD, Chair  
Sandy Feng, MD, Vice Chair  
S. Joseph Kim, MD, FRCPC, Vice Chair**

**Introduction**

The Data Advisory Committee (the Committee) met via Citrix GoToTraining teleconference on 11/08/2017 to discuss the following agenda items:

1. Data Elements of Thoracic Committee Project: Modification of Lung Transplant Follow-Up Form (TRF) to Include CLAD Data
2. Update on the Scientific Registry of Transplant Recipients (SRTR) Contract with Agency for Healthcare Research and Quality (AHRQ) Evidence Practice Center
3. Modify Data Submission Policies Project Planning

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

**1. Data Elements of Thoracic Committee Project: *Modification of Lung Transplant Follow-Up Form (TRF) to Include CLAD Data***

In an effort to create a systematic review process for reviewing data elements, the Committee created the Data Element Standard of Review (Figure 1) in 2016. The Committee also wanted to provide support to committees when they develop proposals that contain data elements to ensure that new data elements are well thought out and collect useful data. In order to pilot these changes, the Committee reviewed the Thoracic Committee's *Modification of Lung Transplant Follow-Up Form (TRF) to Include CLAD Data* proposal before the Thoracic Committee votes to send the proposal out for public comment from January 22, 2018 – March 23, 2018.

Summary of discussion:

The Thoracic Committee sought feedback from the Committee on the *Modification of Lung Transplant Follow-Up Form (TRF) to Include CLAD Data* proposal. The Thoracic Committee Chair presented on the work done by the Thoracic Committee (specifically the Lung Subcommittee) to develop the proposal. The Thoracic Committee utilized the Data Element Standard of Review during the development process. The Thoracic Committee felt that certain current data fields are not helpful and that centers are not utilizing these data fields. The Committee Chair commended the Thoracic Committee for the thorough work on this proposal, and asked about the status field that listed "not applicable" and "unknown" as possible choices, since that may lead to less useful data. The Thoracic Chair appreciated this feedback and said that the Committee may need to look further into the choices in the future because the "not applicable" choice may be unnecessary if patients are all given a spirometry test. The Committee Chair expressed that this issue ties into data submission policies that the Committee is looking into because useful, robust data is necessary for scenarios involving outcomes data and predictive modeling. UNOS staff also clarified that the dropdown list for the status field that includes "not applicable" and "unknown" is consistent with some other forms across UNet<sup>SM</sup>, so it may be more difficult to change this field only on one type of form. The Committee Chair agreed and suggested that as the Committee moves forward with reviewing data elements and data submission, a holistic review may inform wider changes in the future.

While reviewing a data request unrelated to this project, the Thoracic Committee found that one particular data field was answered with “not applicable” or “unavailable” about 50% of the time. The Thoracic Committee Chair wanted to emphasize that we need to be asking for information that is reliable, accurate, and useful over time, especially since centers are often asked to provide a lot of data. When the Thoracic Committee looked at another data field and discovered 20% of the responses were not filled out, they dug further and realized that this 20% came from a very small number of centers. This could inform the data submissions policy project as it may be an opportunity for center specific education.

Overall the Committee found the proposal to be well thought out and that the Thoracic Committee had adequately considered the Data Elements Standard of Review criteria.

**Figure 1: Data Element Standard of Review**

<b>Component or Measure</b>	<b>Criteria</b>
<b>OPTN Data Collection Principles</b>	Is the proposal for collection of this element consistent with at least one of the principles? a) Develop transplant, donation and allocation policies b) Determine if Institutional Members are complying with policy c) Determine Member-specific performance d) Ensure patient safety when no alternative sources of data exist e) Fulfill the requirements of the OPTN Final Rule
<b>Purpose, Population, Outcomes</b>	Have the purpose, population, and intended outcomes of collecting this element been clearly articulated?
<b>Definition and reliability</b>	Is the data element definition sufficiently clear to enable consistent entry? Is the element and collection mechanism designed to consistently reproduce the same results? Are there variations in interpretation that would reduce the utility?
<b>Face Validity</b>	Is the element capable of eliciting the data we seek? Is the data a proxy for the concept you're trying to measure?
<b>Availability</b>	Is this element widely available for the population of patients for which it is sought to be collected?
<b>Alternative Data Sources</b>	Have alternatives to collecting this by the OPTN been explored? Is this element already available via an external source?

Next steps:

The Committee will continue to support OPTN committees on proposals that involve collection or modification of data elements.

**2. Update on the Scientific Registry of Transplant Recipients (SRTR) Contract with Agency for Healthcare Research and Quality (AHRQ) Evidence Practice Center**

The Committee heard an update from the SRTR on their work with the Mayo Clinic AHRQ Evidence Practice Center.

Summary of discussion:

SRTR staff gave the Committee an update on their work with the Mayo AHRQ Evidence Practice Center. The SRTR asked the Mayo AHRQ to look for predictors of outcomes either post-transplant or on the waiting list that are not currently included in OPTN data. The SRTR is in the process of reviewing the results from the study and will provide data elements from that

review to applicable committees. SRTR staff were supportive of an earlier discussion on the need to review current data elements to ensure that the data are useful and up to date.

Next steps:

The SRTR will present the final results of the study at the next Committee meeting

**3. Modifying Data Submission Policies Project Planning**

The Committee wants to send the Modifying Data Submission Policies proposal to the Policy Oversight Committee (POC) and the Executive Committee for project approval.

Summary of discussion:

UNOS staff reviewed the current problem statement for the proposal, which was created when the project first went to the POC and Executive Committee in 2016 but was not approved by the Executive Committee due to resource constraints at the time. The Committee Vice Chair expressed the importance of having an inclusive project that examines all the elements necessary to best modify the data policies but also wanted the Committee to be aware of keeping the project from becoming too large and time consuming. UNOS staff outlined a possible timeline for the project, including work that should be done before the in person meeting on April 4, 2018. The Committee generally agreed with the projected timeline.

Next steps:

UNOS staff will work with the Committee and finalize the project form to send to the POC in January 2018.

**Upcoming Meeting**

- December 21, 2017