

**OPTN/UNOS Data Advisory Committee
Meeting Minutes
September 19, 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 09/19/2017 to discuss the following agenda items:

1. Review of Committee Tasks
2. Update on the Scientific Registry of Transplant Recipients (SRTR) Contract with Agency for Healthcare Research and Quality (AHRQ) Evidence Practice Center
3. Project Review

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

1. Review of Committee Tasks

The Committee reviewed recent work done by the Committee, as well as the roles and tasks of the Committee.

Summary of discussion:

The Committee Liaison briefly reviewed the charge of the Committee and refreshed everyone on recent project work. This included an outline of the data element review process created by the Committee in 2016. The Committee Chair commented that the idea with this process was to pilot it on the *Modification of the Lung Transplant Follow-up Form (TRF) to Include CLAD* project from the Thoracic Committee. The Committee Liaison agreed and will set up a meeting for the Thoracic Committee leadership to discuss this project and their utilization of the Data Elements Standard of Review with the full Committee.

Next steps:

The Committee Liaison will schedule a joint meeting between Thoracic leadership and the Committee.

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 a brief update about the status of their work with the Mayo Clinic AHRQ Evidence Practice Center. The SRTR asked them to look for predictors of outcomes either post-transplant or on the waiting list that are not currently included in OPTN data. The SRTR commented that their internal review should be done within the next couple of months. The Mayo Clinic has produced a preliminary report that the SRTR is currently reviewing. Once they complete the review, they will share the report with the Committee. The SRTR suggested sharing the results with organ specific committees – possibly through a subcommittee with representatives from each of the organ specific committee. The Committee supported this idea.

Next steps:

The SRTR will share the Mayo Clinic's report once they are done with their internal review. A meeting will be scheduled for the Committee to go over the report with SRTR staff. Findings will later be shared with organ specific committees.

3. Project Review

The Committee previously considered several potential project ideas. With the start of the new committee year, Committee leadership wanted to go over these ideas with the new Committee and choose a project to pursue.

Summary of discussion:

UNOS staff reviewed project ideas that the Committee had previously discussed or considered as future Committee work. The *Modify Data Submission Policies* project, which centers on Policy 18: Data Submission Requirements, was not approved by the Executive Committee in April 2016 due to the strategic alignment. At the time, the Executive Committee decided to only move forward with projects in under allocated strategic goals.

A Committee member asked if there were any historical reasons why members are allowed to change their data after they submit it to the OPTN. UNOS staff explained that it was likely due to several factors, including the real need in the community to be able to change data in certain circumstances and also that locking down data after it is submitted would require UNOS staff to go in and make any changes manually if a member needed to change data for valid reasons. UNOS staff also clarified that these reasons could be revisited by the Committee if they wanted to pursue this as a project. Another Committee member commented on the change in the importance of data over the past twenty years and that the transplantation field is now more data driven, which may need to be reflected in any changes to policy. The SRTR commented that members changing data can cause issues with their program-specific reports (PSRs). Several Committee members agreed that an effort to review data elements and standardize definitions would be very helpful as part of this project or as a separate effort. Committee members believe that members in the community may be changing data elements or leaving them blank/incomplete if there is ambiguity in the definition. Committee leadership agreed, and noted that modifying data submission policies would already be a large project and adding the standardization of data elements could make it very large and consequently a slow moving process. One well received suggestion was to start with identifying the elements most likely to be left blank, changed, or cause confusion. The Committee was receptive to having the review of data elements be part of the larger policy review project. By the end of the meeting, the Committee agreed to move forward with the *Modify Data Submission Policies* project, pending a final approval from the Health Resources and Service Administration (HRSA) staff.

Next steps:

The Committee Liaison will wait to hear from HRSA to ensure that this project is within the scope of the Committee's work. If so, the Committee will work to move this project forward for approval from the Policy Oversight Committee and Executive Committee at a later date.

Upcoming Meeting

- November 8, 2017