

**OPTN/UNOS Data Advisory Committee  
Meeting Minutes  
May 11, 2017  
Conference Call**

**Maryl Johnson, MD, Chair  
Sandy Feng, MD, Vice Chair  
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**Introduction**

The Data Advisory Committee (the Committee) met via Citrix GoToTraining teleconference on 05/11/2017 to discuss the following agenda items:

1. Data Submission Project
2. SRTR Contract with Mayo AHRQ Evidence Practice Center

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

**1. Data Submission Project**

The Committee previously considered a project to modify Policy 18: Data Submission Requirements. The Committee reviewed the status of this project.

Summary of discussion:

The Committee liaison reviewed the problem statement that the Committee had crafted at a previous meeting and some potential pathways for moving this project forward. Committee members were supportive of continuing to pursue this project. One Committee member commented that an entire policy revamp was daunting and questioned how the Committee could best approach the project. The Committee member suggested breaking it down into more manageable sections, like by each organ, but another Committee member clarified that sections of Policy 18 are overarching policies while others are organ specific. The Committee agreed that approaching this in smaller sections was a favorable approach. The Committee liaison reminded the Committee of a previous idea to survey primary data coordinators in order to identify best practices. Committee members agreed that this approach would be a good way to address existing problems with the policy that the data coordinators would be able to identify.

One Committee member brought up a previous OPTN committee project aimed at standardizing definitions. The Committee member saw the lack of standardization of definitions on forms to be a pressing issue. The Committee agreed that this issue should be addressed again, and the Committee liaison suggests that the Committee work to create a list of all problems and put them into buckets. This will allow the Committee to more easily tackle similar issues together. The Committee liaison suggests that a standardization of definitions project may be a separate parallel effort to the data submission project.

The Committee liaison also explained that part of the Committee's role is to work with other committees that want to collect new data as part of their projects, ensuring that they are defining things well. The Committee will be piloting this process with an upcoming project from the Thoracic Committee. The Committee will also look into a process for reviewing data that is already collected.

### Next steps:

The Committee liaison will follow up with other UNOS staff on the status of the standardization of definitions project. The liaison will also outline some paths forward for the Committee with the data submission project.

## **2. SRTR Contract with Mayo AHRQ Evidence Practice Center**

The SRTR staff gave a presentation to the Committee about a current project they are working on with the Mayo Clinic.

### Summary of discussion:

The SRTR provided the Committee with a high level overview of a project they are working on with the Mayo Clinic to identify variables through a systematic literature review that predict outcomes and may be useful for the OPTN to collect as data in the future. Though the project is still in progress, the Mayo Clinic has provided the SRTR with around 600 variables identified through their rigorous review process to perhaps predict outcomes. The SRTR will be going through these variables to eliminate those results that are data already collected by the OPTN, and those results that would be impossible for the OPTN to collect. One Committee member asked how this type of review and the results could impact the OPTN. The SRTR staff clarified that certain identified variables could be a place to start with data collection, such as variables that are easy to collect, but that all the variables would need to be vetted to ensure that they are relevant to the OPTN environment. The Committee liaison added that when this project is done and the list of variables is refined, certain variables may be suggested by the DAC to organ specific committees for future data collection projects. The Committee liaison suggests that the SRTR present the final findings to organ specific committees so they are aware of what data may need to be collected in the future as part of a data collection project. The SRTR supported this idea. Additionally, this data may help shorten the evidence gathering stage of data collection projects since the evidence will have already been identified through this SRTR/Mayo Clinic project. The Committee understood that while this addresses improving future data collection, there is still work to be done to review and improve existing data elements.

### **Upcoming Meeting**

- To be scheduled