

**OPTN/UNOS Data Advisory Committee
Meeting Minutes
December 21, 2017
Conference Call**

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

Introduction

The Data Advisory Committee (Committee) met via Citrix GoToTraining teleconference on 12/21/2017 to discuss the following agenda items:

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

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

1. Update on the SRTR Contract with the Mayo 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 reiterated the purpose of the study, which was to ask if there are data elements out there that have been identified in quality studies that predict outcomes, and data elements that we don't already have in the OPTN database.

During its review, the Mayo AHRQ staff asked the question: what are the risk factors of a deceased or living donor transplant, including kidney alone, pancreas, pancreas + kidney, liver alone, liver + kidney, heart, lung, and heart + lung? They looked at two populations: those who got kidney a transplant, looking at post-transplant outcomes, and those who were placed on the waiting list looking at outcomes that would happen on the waiting list. They only considered studies that had at least 1,000 patients because they wanted robust and meaningful outcomes. They also asked what risk factors there are for retrieving deceased donor organs for transplant, but did not find much related to that question. After screening the literature, they ended up with 107 results. Ultimately, a full report was generated with summary tables by each risk factor, which included a rating of the likelihood of bias in the study. This was done for all organs and for both outcomes.

SRTR staff showed a table of the literature review results, which was circulated to the Committee. SRTR staff explained that one caveat of this project is that they may not have identified all of the studies; when a systematic review is done, it is possible to miss studies and there may be some risk factors that really aren't going to be collectable.

SRTR staff presented some possible next steps for what to do with the results. Discussion included the need for an ongoing process, presentations to organ-specific committees, and regular (annual) submissions to the OMB.

One Committee member commented that it looked like the data analysis done by the Mayo group did come up with variables that are not currently being collected by the OPTN. The Committee discussed the feasibility and availability of the data elements, as well as how to update the data elements going forward.

One Committee member commended the Mayo group and the SRTR on the work, and commented that this is something that would be great to do on a regular basis. The member thought it was a great way for Committee members to get involved with some of the organ-specific committees. The member thought the Committee could potentially develop a strategy where it is done on a regular basis. Committee leadership liked the idea of a partnership between DAC and the organ-specific committees to disseminate the data. Another Committee member expressed that it is important for a doctors to take a more active role in seeing how they can improve the data that is collected, including making sure that they are collecting variables that are relevant and getting rid of those not being used. Another Committee member agreed with everyone and added that the OPO Committee should be added and not just the organ-specific committee to see how the additional donor data elements could affect OPOs. The Committee agreed that sharing the data with the OPO Committee was important.

Committee leadership asked what the form update cycle was for the Office of Management and Budget (OMB). Leadership suggested that the Committee could have a different timeline from the OMB if necessary, but could sync up the two timelines if possible. HRSA staff commented that OMB forms get approved for three-year cycles, but that does not mean that one has to wait three years to revise them.

Committee leadership commented that it may be challenging to do the literature search updates in the future due to the volume of work needed. SRTR staff suggested that incremental change in each cycle is likely to be much smaller and therefore much more manageable. The point was made that once the literature searches have been done and there is a strategy that seems to work reasonably well, it may not be too difficult to run the searches periodically to update the results.

Aside from new data elements, the Committee discussed the need for a review of existing data elements to make sure they are still important to collect. The elements that are still important to collect would need to have clear definitions. Finally, the new variables need to be looked at in the same way in terms of how many are feasible to include. The Committee agreed that the whole process would require interaction between members of the Committee, the organ-specific committees, and the OPO Committee.

Next steps:

The Committee will work on a timeline for sharing the data with the organ-specific and OPO committees.

Upcoming Meetings

- February 2018
- April 4, 2018 – Chicago, IL

Attendance

- **Committee Members**
 - Maryl Johnson
 - Sandy Feng
 - Nicole Berry
 - Rick Hasz
 - Eileen Hsich
 - Sumit Mohan
 - Rachel Patzer
- **HRSA Representatives**
 - Joyce Hager
 - Chris McLaughlin
- **SRTR Staff**
 - Katie Audette
 - Bert Kasiske
 - Maryam Valapour
- **OPTN/UNOS Staff**
 - Alison Wilhelm
 - Kimberli Combs
 - Ann Harper
 - Catherine Monstello