

**OPTN/UNOS Data Advisory Committee
Meeting Summary
May 20, 2015
Conference Call**

**Charlie Alexander, Chair
Joe Kim, Vice Chair**

Discussions of the full committee on May 20, 2015 are summarized below and will be reflected in the committee's next report to the OPTN/UNOS Board of Directors. Meeting summaries and reports to the Board are available at <http://optn.transplant.hrsa.gov/>.

Committee Projects

1. Developing an evidence-based decision-making strategy for OPTN registry data elements

UNOS Staff presented a proposed process for reviewing new and existing data elements in alignment with, and identified during, SRTR's program specific report (PSR) 3-year review cycle. Currently, as the SRTR is working on revising the PSR risk adjustment models for a specific organ, the SRTR works with that organ-specific committee to gain insight into the usefulness of the current data elements and whether there are any elements that are highly missing or gameable. If the organ specific committee thinks there are elements that should no longer be collected, or elements that should be collected in the future, the committee must sponsor a public comment proposal to make that change to the OPTN database.

The proposal to modify, remove or collect additional data elements would then be reviewed by the Data Advisory Committee (DAC). The DAC will create standards for reviewing the data collection proposals, particularly to ensure that the proposals are supported by ample evidence, to determine whether they are ready to move forward for public comment.

One DAC member asked about how the OMB approval process fits into the proposed data element review process. The OPTN is working with HRSA to make the OMB process more efficient. HRSA explained that the Tiedi forms could be modified on a more frequent basis, such as once yearly rather than once every three years. HRSA also explained there are some processes to modify the form without a whole revision, as long as it is determined that the change is not substantive. One of the main purposes of the OMB review is to evaluate the burden on the member that must report the data, so if the burden is not substantially increased, there may be more flexibility in collecting additional data. Because of the potential length of time it may take to complete the OMB process, one DAC member asked whether the OPTN could collect certain data elements but not make reporting them mandatory (to avoid OMB requirements). HRSA said this is something that could potentially be considered.

A DAC member then asked, once the data are collected, how long it would take the SRTR to include the data in the risk adjustment models. SRTR estimated it may take an additional year, once the data are collected, to determine how they should be incorporated into the models. However, one SRTR staff member noted that the effect of collecting the additional data may be seen even before the element is incorporated into

the models, because programs may be encouraged to take on additional risk knowing the data element will be accounted for in the future. Additionally, not all data that are proposed to be incorporated into the risk adjustment models will need to be collected by the OPTN; there are other sources of data that may be used to supplement the OPTN dataset and that can be used in the risk adjustment models.

The SRTR also presented a proof of concept for how to conduct a literature search to identify potential new data elements to collect for incorporation into the risk adjustment models.

The proposed next steps are to form a subcommittee of the DAC to create a review process, review the current Principles of Data Collection, create standards for evidence required to support proposals for data collection, and create standards for defining data elements that are reported to the OPTN.

2. DAC OPO Metrics Work Group

A Performance Improvement Work Group at AOPO is working, at the suggestion of CMS, to propose alternative metrics for CMS to use to measure OPO performance. The AOPO Work Group discussed three different measures:

- The current MPSC metric that is used, organs transplanted per donor (yield), is a better measure than the ECD, SCD, and DCD metrics that are currently used by CMS.
- The AOPO Work Group does not plan to propose modifications to the research metric that is currently used.
- The current measure of imminent and eligible donors is controversial and the AOPO Work Group would like to eliminate it. The measure is subjective because it depends upon self-reported data. The Work Group believes better metrics could be developed to assess the effectiveness of OPOs. The Work Group discussed with SRTR different options, including using donors per 1,000 hospital deaths as a starting point, that can be adjusted for other variables (such as age and inpatient ventilated deaths) in the future. The Work Group believe this metric would drive OPOs to work towards managing donor volumes instead of percentages, which may encourage OPOs to use new and innovative ways to recover donors in their area, while also accounting for the yield of organs transplanted.

The next steps are to assemble an OPTN Work Group, including members of DAC, the MPSC and the OPO Committee to evaluate these metrics from an OPO perspective and eventually make a proposal to the OPTN Board of Directors that aligns with modified CMS regulations, which will hopefully lead to improved OPO performance. Additionally, HRSA mentioned the possibility of initiating an OPTN special study to examine these issues.

3. Data Release Policy Revisions

The Data Release Policy Subcommittee has made a number of changes to the current Data Release Policy to ensure it is consistent with the OPTN Final Rule. The Subcommittee's proposed policy language changes, as well as a crosswalk explaining the rationale behind each proposed change, is posted on the SharePoint site. HRSA reviewed these changes and gave initial feedback, which was incorporated into the proposal, and the Subcommittee is awaiting final feedback from HRSA.

The vote to send the proposal for public comment will occur on June 17, so DAC members were encouraged to send feedback prior to June 17 to ensure the feedback could be considered by the whole committee.

Upcoming Meeting

- June 17, 2015