

**OPTN/UNOS Data Advisory Committee**  
**Meeting Summary**  
**June 17, 2015**  
**Conference Call**

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

*Discussions of the full committee on June 17, 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. Data Release Policy Revisions**

DAC previously circulated a draft of proposed changes to the OPTN/UNOS Data Release policy. HRSA provided feedback, expressing concern that the draft Data Release Policy includes too much detail regarding the options for data release based on requestor, and that the policy could not possibly reflect every data request scenario. If the policy fails to cover every potential scenario, the OPTN might be vulnerable and potentially liable to release certain data. HRSA instead recommended that the policy simply contain a statement explaining that the OPTN will follow all applicable state laws and regulations.

In addition to policy, the OPTN would maintain a work instruction or standard operating procedure for processing data requests, as the Final Rule permits the OPTN to evaluate every request for reasonableness. If the OPTN does not find a request to be reasonable, or cannot determine the reasonableness of the request, then HRSA can review and make the decision. The DAC agreed with this position, and stressed the importance of making the work instruction/standard operating procedure available to the public for transparency.

The DAC voted to recommend distributing this proposal for public comment during the Fall, 2015 public comment cycle. (9 approve, 0 oppose, 0 abstentions).

**2. DAC OPO Metrics Subcommittee Update**

DAC OPO Metrics Subcommittee members are working with AOPO and the SRTR to review OPO metrics and measures. These efforts coincide with a CMS effort to incorporate new transplant metrics into their certification process. AOPO CEOs met at a recent meeting and voted unanimously to support the following efforts:

- Eliminate the DCD, ECD, SCD yield measure and replace them with the SRTR observed to expected yield model currently used by MPSC to evaluate yield for OPOs
- Do not propose modifications to the research metric that is currently used (but plan to do so in the future)
- Eliminate the conversion rate measure because it is based on the subjective definition imminent and eligible donors. The measure is subjective because it depends upon self-reported data, it is difficult to audit and interpret, and it is subject to wide variability across DSAs.

In addition to eliminating the current conversion rate measure, the AOPO CEOs voted to support work on a donation rate measure, which measures volumes, to create incentives to increase donor volumes. The starting point should be measuring donors per 1,000 in-hospital deaths, as this measure is auditable and there are external data sets that can validate whether an OPO is reporting all in-hospital deaths in its DSA.

The next steps are to commence a proof of concept data project led by the OPTN/UNOS, the SRTR, and a few OPOs that can provide data to help adjust and improve the model. The data from the OPOs will help with developing age criteria around in-hospital deaths, capturing ventilated in-hospital deaths (and developing a definition for ventilated in-hospital death), and absolute rule out criteria. The proof of concept or feasibility study to determine whether these data could be collected in a standardized way could potentially be led by the UNOS Research Department, depending on the availability of a grant.

The DAC OPO Metrics Subcommittee sought DAC's support in embarking on this project with a work group comprised of the DAC OPO Metrics Subcommittee members, a few members of the MPSC, and a few members of the OPO Committee. DAC approved this path forward and asked for frequent updates.

### **Upcoming Meeting**

- August 19, 2015 at 4pm Eastern