

**OPTN/UNOS Data Advisory Committee
Meeting Summary
January 21, 2015
Conference Call**

**Charlie Alexander RN, MSN, MBA Chair
Joseph Kim PhD, MHS, FRCPC, Vice Chair**

Discussions of the full committee on January 21, 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 Evidence-Based Decision-Making Strategy for OPTN Registry Data Elements

The Data Advisory Committee (DAC) has a number of responsibilities, including analyzing the current data elements in the OPTN database (to be retained, deleted or modified) and evaluating the appropriateness of incorporating future data elements into the OPTN database. Dr. Bert Kasiske, on behalf of the SRTR, proposed a plan for undertaking such a large project. The approach is a “modified PICO” strategy, or “PPPOP”:

- Purpose
- Population
- Prognostic Factor
- Outcome
- Practicality

For each newly proposed data element, DAC would use the PPPOP approach to determine whether the data element should be included in the OPTN database. For “purpose,” the data will most likely be used for program specific reports (PSRs) or for OPTN allocation policy. “Population” will be the transplant group for which the data is relevant (such as kidney transplant recipients). The “prognostic factor,” such as pre-transplant coronary artery bypass grafting, will require evidence to describe its purported significance. The “outcome” is likely to be whether that data element affects patient survival or graft survival. And the “practicality” measure is likely to be the most subjective; is this information readily available and easy to report?

In addition to adopting an approach for analyzing new data, DAC must decide upon certain logistical considerations, such as how to divide the work, and the timeline for performing the work. Dr. Kasiske suggested developing a task list divided up by PPPOP that will cover the existing database, different populations (patients, donors, etc.), and different purposes and outcomes. He also suggested examining whether the timelines for analyzing data could coincide with the timelines SRTR has already established for rebuilding organ-specific PSRs (3-year cycles). Once DAC has enough information to package together a proposal to retain certain data elements or to add new data elements, it can begin the public comment process; this process of packaging data elements for public comment and Board of Director review could eventually become systematic so DAC can present something at every Board meeting or every other Board meeting.

Dr. Kasiske also advised DAC to be conscious of the scope of the project. Though it would be ideal to capture every data element associated with end-organ failure, it may not be practical to do so. The committee should consider whether predictors for outcomes of PSRs should include post-transplant variables, or whether the models should only include factors the transplant program would know at the time of transplant.

Ideally a major literature search supporting this project would be performed through a subcontract with an AHRQ EPC, but such a subcontract is unlikely to come to fruition. Therefore, SRTR is likely to play a large role in supporting the committee through literature searches, and comprehensive reviews of OPTN-linked database analyses and existing SRTR data reviews performed in support of the PSRs. All of this information will help DAC determine the utility of each data element.

DAC members hope to achieve more clarity about the use of the PPPOP approach in examining new data elements during its February meeting. Dr. Kasiske clarified that for current data elements, the PPPOP approach is probably less useful, and instead members would focus on how each current data element is used, and whether there is significant missingness, etc. One DAC member also reminded others of the need to ultimately review the current approach to outcome metrics to determine whether the outcomes currently measured (graft survival and patient survival) are the most useful measures in monitoring the performance of the system.

By the end of the February 10 meeting, DAC will have a plan for analyzing new and existing data elements.

2. OPO Data and Metrics

Charlie Alexander, Chair of DAC, spoke about the challenges of collecting data to measure OPO performance. OPOs, however, want to ensure that they are achieving maximum donor opportunity in the country. Charlie wrote a letter to the Association of Organ Procurement Organizations (AOPO) requesting information about initiatives currently underway regarding data-driven metrics designed to assess OPO performance. The letter was discussed during the AOPO meeting in January 2015, and AOPO should provide a response to be considered during DAC's February 10 meeting in Chicago.

Upcoming Meeting

- February 10, 2015 in-person meeting in Chicago, IL