

**OPTN/UNOS Data Advisory Committee
Report to the Board of Directors
June 1-2, 2015
Atlanta, Georgia**

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

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This report reflects the work of the OPTN/UNOS Data Advisory Committee during the November 2014 to April 2015 period.

Committee Projects

None

Other Committee Work

1. Data Release Policy Revisions

Public Comment: [March, 2012](#)

Public Comment: August, 2015 (Estimated)

Board Consideration: December, 2015 (Estimated)

The Final Rule requires the OPTN Contractor to release to the public “data needed for bona fide research or analysis purposes,” and to “respond to reasonable requests from the public for data needed to assess the performance of the OPTN or Scientific Registry, to assess individual transplant programs, or for other purposes.” The OPTN/UNOS data release policy, which governs the data that may be released to the public and the process for doing so, is more restrictive than the Final Rule; it restricts the release of institution-identified data, even though the Final Rule requires the OPTN to release data to allow the public to assess individual transplant programs, and for other purposes.

The proposed solution is to revise the OPTN/UNOS data release policy to remove restrictions that are not permitted by the Final Rule. Requests for data will still be evaluated for reasonableness by UNOS staff, but the process for doing so does not need to reside in policy. Additional substantive changes to the current data release policy will also be included in the proposal so that policy reflects current data release practices. Finally, the revised policy will also be edited for consistency with plain language principles that govern OPTN policies. The Policy Oversight Committee previously sponsored a public comment proposal to modify the data release policy in March 2012, but the proposal was never presented to the Board for approval.

DAC formed a Data Release Policy Subcommittee to carry out these goals and will present the proposed changes to the full committee during its June 17, 2015 meeting, in anticipation of release for August 2015 public comment.

For more information, see the Data Release Policy Subcommittee meeting minutes from March 18 and April 10, 2015.

2. OPO Metrics

Public Comment: January, 2016 (Estimated)

Board Consideration: June, 2016 (Estimated)

The OPTN's OPO metrics are not in sync with the Center for Medicare & Medicaid Services (CMS) OPO metrics. There is currently an opportunity to revise CMS's metrics and potentially bring the OPTN and CMS metrics into alignment. DAC is currently forming a working group comprising members of DAC, the OPO Committee, and the Membership and Professional Standards Committee (MPSC) to review current OPTN metrics and measures to determine whether they can be improved, and how to align the OPTN metrics and measures with the CMS OPO metrics and measures. Improving the metrics will likely include identifying areas in which additional data collection is needed.

The goal of the project is explore using the observed to expected metric to measure other aspects of OPO performance such as:

- Yield measure
- Conversion/consent rates
- Volume (measure and to understand variability in donors a yet to be determined segment of the population)

For more information, see the DAC OPO Metrics Subcommittee meeting minutes from April 15, 2015.

3. Develop an Evidence-Based Decision-Making Strategy for OPTN Data Collection

The transplant community recognizes the need to improve risk adjustment through program specific reports (PSRs) by collecting additional data, but collecting additional data imposes resource burden on transplant centers, OPOs, histocompatibility labs, and the OPTN. Additionally, the OPTN database may collect data that are no longer relevant or not collect data that are relevant to improving PSRs and the monitoring of OPTN policies, and definitions of data elements are not always clear. Lastly, there is no systematic review process for reviewing data elements in OPTN database.

DAC recognized that this will be a large effort, and considered ways to divide the workload, such as by organ type. DAC agreed that the effort should be divided into review of current data elements and review of new data elements. For new data elements, SRTR performed a "pilot" to test the practicality of performing a systematic literature search to identify potential new elements suggested in published articles. DAC agreed this is a good starting point for the new data collection aspect of the project. The current data element review may be performed in conjunction with the SRTR PSR model rebuild cycle, because the SRTR rebuilds the PSR for each organ every three years, and in doing so reviews the currently captured data and assesses each element's utility.

The DAC also agreed that it will need to reach out to subject matter experts to help provide insight into the utility of current data elements and suggestions for future data elements. These small working groups should also be staffed by representatives from the UNOS IT department and transplant administrators. This will be an ongoing effort, rather than a one-time review of data elements.

DAC has not yet established a timeline for this project.

4. Review of UNOS IT's Plan to Implement a Secure Enterprise Solution for Data Collection and Storage

The UNOS IT Department provided DAC with a summary of its plans to improve the OPTN/UNOS IT infrastructure for collecting data, storing data, and interacting with external sources of data. UNOS IT has been meeting with customers to understand how they use UNetSM and how they use other electronic medical records (EMR) service providers to learn how to better integrate these systems to lessen the burden of entering data into UNet and retrieving data from UNet. The ultimate goal is to automate data transfers between the OPTN data system and the external data sources.

The proposed solution is to build a "data lake." A data lake is a data storage entity that can receive data from many different data sources and does not silo the data. External data sources, such as EMRs, can input and retrieve data from the data lake through application program interfaces (APIs). Because the data in the data lake are not divided into categories, users are able to access and organize the data in a personalized way that makes sense for their needs.

Successful implementation of the automated data exchange would lessen the burden of data entry on transplant centers and OPOs and others who interact with the OPTN database, which would in turn reduce the cost of collecting new data elements. Additionally, the data lake will allow transplant centers and OPOs to have access to more data that is not pre-organized, which will help with their decision-making. The data lake will also make it easier to interact with new data sources that cannot currently interact with UNet. The UNOS IT department will keep DAC updated with its progress.

Meeting Summaries

The committee held meetings on the following dates:

- November 19, 2014
- December 17, 2014
- January 21, 2015
- February 10, 2015

Meetings summaries for this Committee are available on the OPTN website at: <http://optn.transplant.hrsa.gov/converge/members/committeesDetail.asp?ID=58>.