

OPTN/UNOS Data Advisory Committee
Meeting Summary
January 20, 2016
Conference Call

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Discussions of the full committee on January 20, 2016 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 Submission

The DAC continued its discussion of problems related to data submission policies and practices. After summarizing the discussion from the [December 16, 2015](#) meeting, UNOS staff presented additional recommendations for data quality improvements. The presentation outlined three sources of data integrity issues in the OPTN dataset: 1) timeliness; 2) stability; and 3) reliability.

- Timeliness speaks to the time in which programs are either permitted or required to report data to the OPTN, and timeliness is typically governed by OPTN policies. Current policies may create confusion for members, as there are various timelines associated with submitting data to the OPTN. These policies may also create an impression that the timeframes for submitting data to the OPTN are not important.
- Stability relates to how the data are changed after they are reported to the OPTN. The SRTR's presentation from the December 16, 2015 teleconference shows there is a problem with the stability of the data in the OPTN dataset, as elements are often changed after they are reported. Additionally, the OPTN permits data to be reported as unknown or unavailable, which may also make the data less stable.
- Reliability relates to whether the OPTN dataset contains data one would expect to see. Objective data points and clear field level definitions are critical to achieving reliability, but current definitions may be too vague and certain data points may be too subjective.

Current policies and practices evolved from a time when data were submitted to the OPTN on paper forms, and UNOS staff would manually enter data on behalf of members and request that members validate the data after entry. However, past behavior should not necessarily continue to inform current and future data collection. In alignment with the OPTN Data Vision Statement, also discussed during December's call, UNOS staff suggested that the goals of the Data Submission project should be to achieve integrity, timeliness and stability in the data system so that OPTN data used for any purpose (program specific reports, policy development, research, etc.) help achieve accurate results.

Staff recommended that DAC work to solve the first problem of timeliness by revising the data submission policies and that DAC create a standard of review for achieving reliability of data elements in the OPTN system. As a parallel effort, SRTR and UNOS staff, with advice from DAC and the Transplant Administrators Committee and

Transplant Coordinators Committee, can review existing field definitions and make them clearer. UNOS and SRTR staff are also examining why data are being changed, to help determine whether the data can be more stable.

Next Steps:

During February's teleconference, DAC members will form two subcommittees. The first will be a Data Submission Policy Subcommittee, which will focus on current OPTN data submission policies and suggest revisions. The second will be a Data Element Review Subcommittee, which will create a standard of review for new (and potentially existing) data elements in the OPTN system, in alignment with the OPTN data vision statement and Principles of Data Collection. Both subcommittees will explore the wide range of potential solutions suggested by DAC members during this teleconference.

Upcoming Meetings

- The Committee meets the third Wednesday of every month at 4pm Eastern.