OPTN/UNOS Data Advisory Committee Meeting Summary October 06, 2016 Conference Call

Maryl Johnson, MD, Chair S. Joseph Kim, MD, FRCPC, Vice Chair

Discussions of the full committee on October 6, 2016 are summarized below. All committee meeting summaries are available at https://optn.transplant.hrsa.gov.

Committee Projects

1. Data Vision Statement Project

The Data Advisory Committee (the Committee) reviewed a draft of the OPTN Data Vision Statement that lays out the long-term vision for the OPTN data system. The Committee made changes to the vision statement by fixing grammatical issues, adding patients to the stakeholders addressed in the statement, requesting that data collection be timely, and removing a request that data collection be downloadable. The Committee kept the bulleted elements regarding data collection in the statement, agreeing that these elements help to expand on the vision for future data.

After making these minor edits, the Committee voted with unanimous consent to approve the OPTN Data Vision Statement and send it to the Board of Directors in December. A first draft of the statement will be submitted by October 31st.

Upcoming Meeting

No Full Committee Meeting is scheduled at this time.

OPTN Data Vision Statement

The OPTN collects information in accordance with the Final Rule: 1) to characterize the population it serves; 2) to improve the allocation and utilization of organs; and 3) to develop and assess policies and processes to optimize outcomes. The overall intent is to provide value to patients, OPTN members, the organ donation/transplantation community, and the general public.

- Whenever possible, data collected in center or OPO electronic health records, and other databases should be accessible to the OPTN without the need for additional data entry.
- Variables collected should specifically support the data uses outlined above and should be re-evaluated on a regular basis.
- Data collected should be accurate (based on clear definitions), complete, timely, and subject to ongoing quality control audits/efforts.