

## Mini-Brief

# OPTN Data Vision Statement

*OPTN/UNOS Data Advisory Committee*

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# OPTN Data Vision Statement

*Affected Policies:* N/A  
*Sponsoring Committee:* Data Advisory  
*Public Comment Period:* N/A

## Executive Summary

HRSA requested that the OPTN create a vision statement for the future of the OPTN data system that analyzes and considers advances in both organ transplantation and technology. The OPTN currently does not have a data vision statement, and without one, it is difficult for the organization to strategize and prioritize efforts related to data collection. Creating a data vision statement promotes the efficient management of the OPTN by allowing the OPTN to make data-related decisions that are aligned with organizational goals.

## What problem will this proposal solve?

The OPTN currently does not have a data vision statement, and without one, it is difficult for the organization to strategize and prioritize efforts related to data collection. HRSA requested a vision statement for the future of the OPTN data system that analyzes and considers advances in both organ transplantation and technology.

The new OPTN data vision statement will supplement the existing OPTN Principles of Data Collections and operational statements, which were approved by the OPTN Board of Directors in December 2006 to ensure that all OPTN data collection supports the organization's core missions.

### Currently existing OPTN Principles of Data Collection:

Institutional members must provide sufficient data to OPTN to allow it to:

- a) Develop transplant, donation, and allocation policies;
- b) Determine if Institutional Members are complying with policies;
- c) Determine Member-specific performance;
- d) Ensure patient safety when no alternative sources of data exist; and
- e) Fulfill the requirements of the OPTN Final Rule.

### Current operational statements for data collection:

1. The OPTN will only collect data that is contracted by HRSA.
2. Data collected and submitted by Institutional Members to the OPTN may differ in nature and character for specific populations, forming exceptions to Guiding Principles above (e.g. Pediatrics, Living Donors). For these exceptions to the foregoing principles, alternative sources of information must be explored and supported, duplication of existing efforts (e.g. registries) avoided, and sample data collection considered. The need and purpose of any such exceptions must be clearly articulated and subject to Policy Oversight Committee and Board approval, and public comment.
3. All future data requests by OPTN committees must be justified in the context of the above guiding principles, and new data collection will require approval by the Policy Oversight Committee and the Board of Directors of the OPTN, and be subject to public comment.

## Why should you support this proposal?

Creating a data vision statement provides the OPTN with focus related to future OPTN data collection. The OPTN/UNOS Data Advisory Committee (DAC) worked closely with the Scientific Registry of Transplant Recipients (SRTR) and HRSA to ensure that the Data Vision Statement conceives of and addresses all potential uses of OPTN data. DAC members agreed that the vision statement should:

- Reflect where the community will be 10 to 15 years from now
- Allow for expansion as the field of transplantation changes
- Maintain flexibility
- Utilize new technologies

The Committee discussed different parameters it felt should be included as goals in the vision statement, including:

- Reducing redundant data capture
- Improving the integrity of data by maintaining the OPTN policy and procedures
- Developing universal data infrastructure for the OPTN that is consistent with the broader healthcare community

- Increasing integrity of OPTN data for the purpose of improving government utilization and facilitating compliance
- Adopting new technologies to enhance usability and allow for standardization with non-OPTN sources when possible

The DAC then brainstormed concepts that should be included in the vision statement, including:

- Increasing/optimizing/leveraging other data sources.
  - Supplementing with external sources
  - Populating data core elements in OPTN database that could be derived from external sources
  - Consistency with other sources
- Accessibility: (once the data are collected, how can the data be made maximally accessible?)
- How the data are used (on top of allocation, outcomes reviews, are there things in the future that the data could also assist us with?)
- Accuracy and completeness
- Clear definitions
- Quality checks to validate data
- Edit checks or limits built into system
- Learning data system
- Process for creating a feedback loop for reporting to the OPTN when others find that there are missing data or data the OPTN should collect
- Data governance
- Focus on future state

The Committee then drafted a short vision statement that encapsulates the principles and goals outlined above. As vision statements are meant to be a roadmap for an organization, the DAC agreed the vision statement itself should be concise, while the strategy for implementing the vision will be more detailed. The Committee ultimately agreed on the proposed version during its teleconference on October 6, 2016.

## How does this proposal impact the OPTN Strategic Plan?

1. *Increase the number of transplants:* There is no impact to this goal.
2. *Improve equity in access to transplants:* There is no impact to this goal.
3. *Improve waitlisted patient, living donor, and transplant recipient outcomes:* There is no impact to this goal.
4. *Promote living donor and transplant recipient safety:* There is no impact to this goal.
5. *Promote the efficient management of the OPTN:* A clear data vision statement will allow the OPTN to make data-related decisions that are aligned with organizational goals.

## How will the OPTN implement this proposal?

Future decisions about OPTN data collection will be guided by the OPTN data vision statement. This proposal will not require programming in UNet<sup>SM</sup>, and no other OPTN resources will be required for implementation.

## How will members implement this proposal?

Members will not need to make any operational changes as a result of this proposal, and there should be no fiscal impact on members. Members might want to consider the Data Vision statement along with the Principles for Data Collection when they request new data collection proposal to the OPTN.

## **Will this proposal require members to submit additional data?**

The OPTN data vision statement will be used to guide OPTN data collection in the future, but this proposal does not require additional data collection.

## **How will members be evaluated for compliance with this proposal?**

Members will not need to make any operational changes, and there will be no evaluation for compliance needed as a result of this proposal.

## OPTN Data Vision Statement

**RESOLVED, that the OPTN Data Vision Statement, as set forth below, is hereby approved, effective December 6, 2016.**

- 1 The OPTN collects information in accordance with the Final Rule: 1) to characterize the population it  
2 serves; 2) to improve the allocation and utilization of organs; and 3) to develop and assess policies and  
3 processes to optimize outcomes. The overall intent is to provide value to patients, OPTN members, the  
4 organ donation/transplantation community, and the general public.  
5
- 6 • Whenever possible, data collected in center or OPO electronic health records, and other databases  
7 should be accessible to the OPTN without the need for additional data entry.  
8
  - 9 • Variables collected should specifically support the data uses outlined above and should be re-  
10 evaluated on a regular basis.  
11
  - 12 • Data collected should be accurate (based on clear definitions), complete, timely, and subject to  
13 ongoing quality control audits/efforts.

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