

**OPTN Data Advisory Committee  
Holistic Data Review Workgroup  
Meeting Summary  
March 24, 2023  
Conference Call**

**Jesse Schold, PhD, M.Stat., M.Ed., Chair**

## **Introduction**

The Holistic Data Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 03/24/2023 to discuss the following agenda items:

1. Discuss Workgroup Meeting Frequency
2. 02/24 Meeting Highlights
3. Data Definition Requests

The following is a summary of the Workgroup's discussions by topic area.

### **1. Discuss Workgroup Meeting Frequency**

The Workgroup reviewed the upcoming Workgroup meeting dates, as follows:

- April 28, 2023, 1:00 to 2:30 pm (ET)
- May 22, 2023, 1:00 to 2:30 pm (ET)
- June 23, 2023, 1:00 to 2:30 pm (ET)

### **2. 02/24 Meeting Highlights**

The Workgroup reviewed meeting highlights from the February 24, 2023 Workgroup meeting. During this meeting the Workgroup performed a data analysis exercise regarding primary diagnosis and disease recurrence data elements. The Workgroup discussed whether these data elements could be mapped to ICD and the potential benefits of mapping and leveraging health care term standards to measure pre and post transplant outcomes.

#### Summary of discussion:

A member suggested asking transplant programs which systems are utilized by transplant programs across the nation for medical records. Another member shared their experience with their transplant program that utilizes ICD-10. The member explained that matching the population needs to transplant service planning is based on ICD-10. Staff summarized that a benefit of mapping diagnosis codes to ICD-10 would allow for transplant programs to review the distribution of their services to population needs and identify where gaps may exist. The member confirmed and added that this is part of business planning.

Another member noted that transplant programs collect various social determinants of health data, such as homelessness or insurance coverage, that may not be mappable to ICD-10.

### 3. Data Definition Requests

The Workgroup discussed two data definition requests related to clinical events and source of payment.

#### Summary of discussion:

##### *Clinical Events: Events occurring between listing and transplant*

A member suggested that modifying the data definition to say “transplant time” may add clarity.

Another member noted that this data element is related to time of listing and transplant, so the time frame of “2 weeks prior to transplant” in regards to infections requiring IV therapy, may not be appropriate. A member suggested that if “2 weeks prior to transplant” is necessary to keep, then it should be reworded to state “14 days prior to transplant” for further clarity.

Another member suggested that the “start of organ anastomosis” should be defined. The member said there are various interpretations for the “start of organ anastomosis”. A member responded that their transplant program defines “start of organ anastomosis” as when the first stitch is sewn between the transplanted organ and the recipient. Another member responded that it may be beneficial for the OPTN to have a standard definition.

A member suggested changing the “date of transplant” to “time of anastomosis” or “time of completed transplant” to be very clear on the timeframe of events that should be captured. The member stated it depends if events are to be collected prior to transplant or upon completion of transplant. Another member agreed.

A member asked why this data is collected. Another member responded that this data is used for analyzing graft survival and measuring risk adjustment.

Members reviewed the project *Data Collection to Evaluate Organ Logistics and Allocation*, which is OPTN Board of Director approved and pending implementation.<sup>1</sup> This proposal defined time of transplant as an organ transplant begins at the start of anastomosis or start of an islet infusion. This data element would collect the time in a 24-hour format.

##### *Source of payment*

A member agreed with the proposed modifications.

Another member stated it is appropriate to state that for individuals to be eligible for Medicare Advantage, they must be eligible for Medicare. The member explained it is appropriate to state that because often the staff entering the forms are not familiar with insurance coverage requirements.

A member suggested that “unknown” response option should be modified to say “no insurance”. Another member noted that it is very rare for an individual without insurance to undergo transplant.

A member suggested to add examples to the “free care” response option, such as charity care. The member also suggested that the response option for private insurance may benefit from noting that includes commercial insurance. A member agreed.

A member suggested that the response option “self” should be modified to “self-pay.”

A member suggested that the response option “Private Insurance” should be modified to include “Commercial Health Insurance.”

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<sup>1</sup> OPTN Operations & Safety, *Policy Notice*, Data Collection to Evaluate Organ Logistics and Allocation. Public comment period, August 2, 2021 – September 30, 2021. Available at [https://optn.transplant.hrsa.gov/media/5accb1s3/policy-notice\\_osc\\_data-collection.pdf](https://optn.transplant.hrsa.gov/media/5accb1s3/policy-notice_osc_data-collection.pdf).

A member suggested changing the “capitated fee” term to “predetermined rate” in the public insurance definition.

Next steps:

After the Holistic Data Review Workgroup validates the data definition requirements, the revised data definitions will be presented to the OPTN Data Advisory Committee for endorsement

#### **Upcoming Meetings**

- April 28, 2023, 1:00 to 2:30 pm (ET)
- May 22, 2023, 1:00 to 2:30 pm (ET)
- June 23, 2023, 1:00 to 2:30 pm (ET)

## Attendance

- **Committee Members**
  - Christine Maxmeister
  - Colleen O'Donnell-Flores
  - Krishnaraj Mahendraraj
  - Rebecca Baranoff
- **UNOS Staff**
  - Brooke Chenault
  - Eric Messick
  - Janis Rosenberg
  - Krissy Laurie
  - Lloyd Board
  - Nadine Hoffman
  - Sevgin Hunt