

**OPTN Data Advisory Committee  
Holistic Data Review Workgroup  
Meeting Summary  
April 28, 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 04/28/2023 to discuss the following agenda items:

1. Discuss Workgroup Meeting Frequency
2. Old Business: Validate the Requirements
3. New Business: Clarify the Definition for Patients on Insulin
4. Clinical Data Standards Project Update

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:

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

### **2. Old Business: Validate the Requirements**

The Workgroup reviewed feedback on data definition changes from the March 24, 2023 Workgroup meeting.

#### Summary of discussion:

In regard to the data definition for *clinical events* a member noted that their transplant program defines anastomosis as the time the first stitch was sewn. Another member agreed and stated that is the reason why anastomosis was determined to be the start of transplant.

In regard to the data definition for *source of payment*, a member stated that a patient would not be listed with emergency Medicaid because it does not cover transplant. Another member asked if states have different variations in emergency Medicaid coverage for non-citizens.

A member asked whether insurance through the Affordable Care Act (ACA) should be distinguished in the list of response options.

Another member noted that *no insurance* is the same as *self-pay* because an individual without insurance coverage would have to pay out of pocket for the transplant services. Members agreed to remove one of the response options to reduce confusion.

A member noted that there has been a rapid acceleration of patients with Medicare Advantage, and it may be beneficial to capture data on this in order to understand the changing population.

Another member noted that the data definition should be the same across all forms for ease of data entry. The member added that additional clarity for *Medicare fee for service* and *Medicare & Choice* would be beneficial for transplant staff filling out the form. An SRTR representative agreed and suggested that instead of *Medicare & Choice* it should state *Medicare Part C* or *Medicare Advantage*.

The Workgroup agreed there is no essential need to document secondary insurance for OPTN purposes.

#### Next steps:

Feedback from this meeting and the March 24, 2023 Workgroup meeting will be incorporated into updated data definitions. The revised data definitions will be presented to the OPTN Data Advisory Committee for endorsement.

### **3. New Business: Clarify the Definition for Patients on Insulin**

The Workgroup discussed a data definition request related to patients on insulin.

#### Summary of discussion:

A member noted support for modifying the “day insulin initiated” more general. The member explained that it is highly unlikely that accurate dates are reported because no one is aware of the exact date of when insulin was first initiated. The member stated that “year initiated” or “age” is a more appropriate way to collect the data.

Another member stated that staff is more likely to enter an approximate date than enter “unknown”.

An SRTR representative suggested adding a checkbox for staff to indicate whether the date is approximated.

In regard to average total insulin use per day, a member suggested to identify a time period in order to define what average means. The member explained that insulin use by day can vary greatly. The member added that there should not be an upper limit on the number allowed to be entered.

Another member noted that the variability between long-term, short-term, and sliding scale insulin use is so large, that the validity of this data is questionable.

#### 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

### **4. Clinical Data Standards Project Update**

The Workgroup reviewed the project plan for the clinical data standards projects. The Workgroup will help inform the development of an incremental implementation roadmap to adopt clinical data standards by discovering the advantages and challenges of adopting data standard through member interviews and OPTN data analysis. This activity will help inform the holistic data review project by understanding the how to approach and standardize data as well as the sequencing of data review.

#### Summary of discussion:

A member asked who will be a part of the member interviews. Staff responded that it will include clinical teams and IT support staff within transplant programs. The member explained that the vendors who build Application Program Interfaces (APIs) work independently from those who are mapping the data.

Another member asked why histocompatibility labs were not identified for member interviews. It was confirmed that histocompatibility labs will be included.

The member also asked for the reasoning behind including the OPTN Ad Hoc Disease Transmission Advisory Committee. Staff stated that the members of the OPTN Ad Hoc Disease Transmission Advisory Committee represent a wide range of expertise and their input on data may be valuable.

A member suggested including transplant hospital planning departments as bulk data consumers. The member also suggested including the existing data portal.

Next steps:

The members will participate in interviews to help inform the clinical data standards project.

**Upcoming Meetings**

- 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
  - Jesse Schold
  - Karl Neumann
  - Rebecca Baranoff
- **HRSA Representatives**
  - Adriana Martinez
  - Ajay Israni
- **SRTR Representatives**
  - Jon Snyder
- **UNOS Staff**
  - Eric Messick
  - Huong Cunningham
  - Jonathan Chiep
  - Kim Uccellini
  - Krissy Laurie
  - Laura Schmitt
  - Nadine Hoffman
  - Sevgin Hunt