

**OPTN Data Advisory Committee  
Holistic Data Review Workgroup  
Meeting Summary  
December 9, 2022  
Conference Call**

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

## **Introduction**

The Holistic Data Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 12/09/2022 to discuss the following agenda items:

1. Introductions
2. Refresh on Deliverables and Timeline
3. New Parking Lot items for feedback on Workbook
4. Discuss Committee Stewardship Responsibilities

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

### **1. Introductions**

Enterprise Data Management (EDM) introduced new staff in the EDM department that will be assisting the workgroup. Another member from the Data Advisory Committee (DAC) joined the meeting and introduced himself.

### **2. Refresh on Deliverables and Timeline**

EDM staff reviewed the deliverables of the workgroup, including a high-level overview of the final plan for the OPTN Board of Directors. The workgroup reviewed the timeline and noted that the DAC will be discussing the Holistic Data Review project during their in person meeting on February 2, 2023. Workgroup members will be invited to call in and join that portion of the meeting.

### **3. New Parking Lot Items for Feedback on Workbook**

Two members shared they recently added new parking lot items. EDM staff indicated they would review the new items and prepare for discussion in a future meeting. A workgroup member asked an additional question not captured in the current parking lot tab in the workbook.

#### Summary of discussion:

A member asked if the group has considered how exceptions for each organ will be considered, whether that will remain as an organ-specific review process or be evaluated for all organs at once. EDM staff noted that some information is consistent across all organ types, while other data is specific to the organ and often includes qualitative data through exception narratives. Staff will look into these processes internally and follow up with the workgroup at a future meeting.

### **4. Discuss Committee Stewardship Responsibilities**

The workgroup considered what the responsibilities and expectations should be for the OPTN Committees who are responsible for a data subject area.

#### Data summary:

As the Committee Steward for the OPTN subject area, the Committee, with the support of staff, ensures the data produced in their subject area is well defined, of high quality, and fit for use as defined by the OPTN and data consumers in the community.

#### *Committee Stewards*

- Serve as subject matter experts (SME) for data in their subject area
- Lead ongoing management of data elements in their subject area (e.g., standardization, changes, removal, etc.)
- Resolve member questions or concerns about the data
- Review data quality monitoring on critical data in their subject area and share reports with community
- Advise on resolution of data defects (issues)
- Consider proposed changes from other Committees to data in their subject area; provide feedback/support
- Provide input on data collection burden by gathering input from stakeholders (required by OMB)
- Facilitate regular communications to community regarding data changes and defects

#### Summary of discussion:

With regard to the second bullet point, a member commented that while the assigned Committee may have clinical or operational expertise they do not have the familiarity and experience with data. The member suggested developing a set of guiding principles for data management standards to ensure the work taken on by other OPTN Committees is consistent with the data quality expectations set by the DAC. EDM staff agreed and suggested revising 'lead' to 'participate in.'

With regard to the third bullet point, the workgroup discussed the process for reviewing an answering member questions. EDM staff provided the example of the recent HBV Vaccination definition change which was done collaboratively between the OPTN Ad Hoc Disease Transmission Advisory Committee (DTAC) and the DAC. A member suggested replacing 'resolve' with 'consult' to clarify the process that is undertaken.

The group discussed the fourth bullet point and emphasized the importance of regular and ongoing data quality monitoring, outside of just the DAC. Members suggested other OPTN Committees should engage in regular data quality review and work in tandem with the OPTN Membership and Professional Standards Committee (MPSC) to ensure that data quality metrics align with organizational standards.

#### **Upcoming Meeting**

- January 13, 2023
- January 27, 2023
- February 10, 2023
- February 24, 2023

## Attendance

- **Committee Members**
  - Ashley Cardenas
  - Christine Maxmeister
  - Colleen O'Donnell-Flores
  - Jesse Schold
  - Michael Ison
  - Rebecca Baranoff
- **HRSA Representatives**
  - Adrianna Martinez
- **SRTR Staff**
  - Bert Kassiske
  - Jonathan Miller
- **UNOS Staff**
  - Janis Rosenberg
  - Laura Schmitt
  - Michael Hollister
  - Nadine Hoffman
  - Robert Hunter
  - Sevgin Hunt
  - Sharon Shepherd