

**OPTN Data Advisory Committee  
Holistic Data Review Workgroup  
Meeting Summary  
November 4, 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 11/04/2022 to discuss the following agenda items:

1. Workgroup activities

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

### **1. Workgroup activities**

The workgroup primarily discussed parking lot items from the excel spreadsheet and aligning data subject areas with the appropriate primary OPTN Committees. The workgroup continued discussing the potential DAC standing subcommittee to review and maintain the framework this workgroup is developing.

#### Summary of discussion:

##### *Review remaining parking lot items*

A new tab, titled 'data risk,' was added to the workbook. Members are asked to log instances of data risk or data issues they have been made aware of in the community. This tab will help inform how to sequence and prioritize data review projects going forward.

Members discussed functional status and considered whether it could be appropriately assigned to the assessment data or health status and agreed that assessment data was the appropriate data subject area. The workgroup considered waitlist time modifications and felt that it did not align with an existing data subject area but agreed that it should be its own data subject area. A member shared that at their transplant program data coordinators review wait time modifications, but based on the OPTN committees the Transplant Coordinators Committee (TCC) may be the best Committee to be responsible for this data subject area.

##### *Review data subject areas and alignment to primary OPTN Committee*

The workgroup discussed lab data for donors. The group agreed that the Organ Procurement Organization (OPO) Committee would review data for deceased donors. The Living Donor Committee would take the lead for reviewing living donor data. The Histocompatibility Committee will review data pertaining to tissue typing and HLA. In terms of organ verification, the workgroup identified the joint effort between the OPO and the transplant hospital. As such, the workgroup felt that the Operations and Safety Committee may be the best fit as the primary Committee and OPO and TCC as stakeholder committees.

The workgroup discussed exceptions and agreed that each specific organ Committee should be responsible for these, but could consult with the DAC subcommittee for consistency. Members noted

the variability between organ types and whether they have a standard criteria for automatic exception points or are based on a peer-reviewed narrative. The workgroup identified the Operations and Safety Committee as the primary for organ transportation.

The workgroup discussed candidate pre-transplant and post-transplant data. In terms of post-transplant data, a member shared their center has post-transplant data coordinators but the form also includes some pre-transplant information. The workgroup identified the TCC as primary for both. Members noted that all living donor specific data should be overseen by the Living Donor Committee. The Operations and Safety Committee was identified as primary for patient safety data. However, the Ad Hoc Disease Transmission Advisory Committee would oversee infectious diseases and the OPO Committee would be a stakeholder for donor-derived issues.

The workgroup discussed data burden and who would be responsible for reviewing data burden across forms. In the data review and approval process, the Office of Management and Budget (OMB) considers data management as part of their review process. However, as part of the Committee review process the Transplant Administrators Committee (TAC) would be the appropriate group to review for data burden.

Members noted that the burden could vary based on the size of the program. The group emphasized the importance of being intentional and purposeful of the data that is collected by the OPTN. This recommendations aligns with the work being done by the Enterprise Data Management (EDM) department to develop a standard format for data definitions.

*Discuss potential criteria to use for establishing on-going DAC advisory group to assist other OPTN Committees pursuing data review/collection projects*

During the last meeting, the workgroup discussed developing a standing DAC subcommittee that would monitor the data subject areas assigned to DAC and advise other Committees on data quality standards. If created, this subcommittee would be responsible for reviewing and advising on changes to data that is used by multiple areas and multiple organs. This will help ensure that the modification of data in one specific arena is consistently modified across organs and data collection forms. Examples of these types of DAC subcommittee led data modifications are patient ID, vitals, body measurements, or demographics. Some potential skillsets have been added to the workbook for the group to review and provide their input in.

### **Upcoming Meeting**

- November 18, 2022
- December 2, 2022

## Attendance

- **Committee Members**
  - Christine Maxmeister
  - Colleen O'Donnell-Flores
  - Karl Neumann
  - Krishnaraj Mahendraraj
  - Rebecca Baranoff
- **HRSA Representatives**
  - Adrianna Martinez
  - Chris McLaughlin
- **SRTR Staff**
  - Bert Kassiske
  - Jon Snyder
- **UNOS Staff**
  - Brooke Chenault
  - Eric Messick
  - Janis Rosenberg
  - Kim Uccellini
  - Krissy Laurie
  - Laura Schmitt
  - Nadine Hoffman