OPTN ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK

Meeting Summary

OPTN Data Advisory Committee
Holistic Data Review Workgroup
Meeting Summary
November 18, 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 11/18/2022 to discuss the following agenda items:

1. Workgroup activities
2. Workgroup homework and next steps

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

1. Workgroup activities

Enterprise Data Management (EDM) introduced the agenda for the meeting, which will focus on the primary activities of the workgroup: reviewing parking lot items and the Principles of Data Collection and Data Vision Statement.

Summary of discussion:

Review remaining parking lot items

A member recommended developing a master patient ID that links to all patient events simultaneously to reduce data quality risks. This integrated patient ID would connect living donor, recipient, and deceased donor records to consolidate the various ways that one individual could be involved in the transplant allocation system. The workgroup Chair referenced the PERS_ID (unique person ID for patient), which is developed by the SRTR using a person-matching algorithm. There was another question in the parking lot about social support, but the question was vague and the member who submitted the question was not on today's call. As such, the group opted to table this question for another meeting and EDM staff will look into the requirements for social support data.

Workgroup discussion of Principles of Data Collection and Vision Statement

EDM staff clarified that the workgroup does not need to have the answer to revising these statements now, but if the group thinks it would be appropriate to modify them then that recommendation can be included in the holistic data review framework for the OPTN Board of Directors and could be a project taken on by the Data Advisory Committee (DAC). A member echoed the sentiment that having an overarching consistent plan for regular data review and identifying who should perform the regular data review would be valuable to include in the Principles of Data Collection and Data Vision Statement.

With regard to the Principles of Data Collection, a member asked for clarification on number 1 of the operational statement for data collection which requires "the OPTN will only collect data that is contracted by HRSA." The member inquired if this restricted data collection to primary data or if it included secondary data as well. EDM staff responded that the operational guidelines do not make a distinction between primary and secondary data, rather they allow any data that is necessary for OPTN function and approved by the Office of Management and Budget (OMB).

With regard to the Data Vision Statement, a member inquired if there is a technical definition for ‘the population it [OPTN] serves.’ The member added that there is no consensus within the community about what population the OPTN serves, which could impact the data that is collected and how it is evaluated. A member inquired about the statement that data “should be accessible to the OPTN without the need for additional data entry,” specifically asking for clarity about what is meant by ‘without the need for additional data entry.’ A member noted that this would require significant collaboration with electronic health record (EHR) vendors to ensure that transplant centers are not doing duplicative data entry. The member added that this would require substantial resources from both EHR vendors and transplant centers, thus creating some challenges to practical implementation.

The workgroup Chair recommended a formal auditing system that would maintain a high level of data quality across the OPTN. The Chair recommended auditing based on clinical and medical criteria, such as accurate disease etiology and biologically implausible ranges. A member inquired if these audits would occur in addition to the OPTN site surveys, which occur once every three years. A member shared their center’s requirement for a two-person data validation check before submitting any OPTN forms. Another member added that the site survey process is a very intensive process and some centers likely would not have the staff to support additional audit processes. The workgroup Chair suggested the group learn from the site surveys to identify if there are sections of data that are particularly vulnerable to inaccurate documentation. Members agree they do not want to be redundant in work or place excessive data burden on centers.

The Chair asked for a refresher on the data burden component. As part of the OMB review process, the EDM department has developed a pilot with the OPTN Transplant Administrators Committee (TAC) where they review each form and provide feedback on data burden.

2. Workgroup homework and next steps

Members are asked to review the sheet of the workbook titled “DAC Sub-Comm Make-up” and provide feedback and recommendations for the tasks and responsibilities of that subcommittee. This subcommittee will review the data subject areas that are assigned to the DAC through the holistic data review framework.

Upcoming Meeting

- December 2, 2022

Attendance

- **Committee Members**
    - Ashley Cardenas
    - Christine Maxmeister
    - Jesse Schold
    - Karl Neumann
    - Rebecca Baranoff
- **HRSA Representatives**
    - Adrianna Martinez
- **SRTR Staff**
    - Jonathan Miller
- **UNOS Staff**
    - Brooke Chenault
    - Eric Messick
    - Kim Uccellini
    - Krissy Laurie
    - Nadine Hoffman