

Meeting Summary

OPTN Data Advisory Committee
Holistic Data Review Workgroup
Meeting Summary
October 28, 2022
Conference Call

Jesse Schold, Ph.D., M.Stat., M.Ed., Chair

Introduction

The Holistic Data Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 10/28/2022 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) staff introduced the workbook for the group's discussion today, which focused primarily on Critical Criteria and working through the parking lot section.

Data summary:

Criteria for critical OPTN Data: Critical data elements are identified by the criteria listed below and expect the highest level of data quality.

- Support critical OPTN business process
- Data used for external reporting to a federal agency or regulatory body

OPTN Critical Business Processes (CBP) are essential for carrying out the operations of the OPTN.

Summary of discussion:

A member identified organ verification data collected pursuant to Policy 5.8: Pre-Transplant Verification as critical to supporting the OPTN's business processes. The information collected is primary source verification used in DonorNet to identify vital data for the donor-recipient organ match. The member added that this form is populated with vital information and transplant hospital staff is required to confirm the accuracy. The member identified limitations with this form, noting that it only populates for deceased, non-directed, single organ transplant and does not populate for living donors, directed donors, or multi-organ transplants. The member recommended having a discussion with the Operations and Safety Committee about how they use information from the form about issues involving blood type. Similarly, a discussion with the Histocompatibility Committee about how their process for reviewing CPRA-related issues might also be useful.

The group reviewed the parking lot section of the workbook and discussed a question about pediatrics, whether pediatric data is a subset of existing subject areas and managed by the same Committee or if it is unique and needs to be assigned to the OPTN Pediatric Transplantation Committee. In order to align and not duplicate work, it would be beneficial for the primary assigned Committee to oversee the data but include representation from the Pediatric Committee to ensure those interests are represented and consulted.

EDM staff inquired if the body measurement category could be combined into the vital signs category, but a member responded saying this would be not clinically intuitive. The workgroup discussed ABO blood group data and identified it as a critical piece of information that requires its own category, or could possibly be included with lab data. The group agreed that the OPTN Histocompatibility Committee would suffice as the responsible Committee. A member suggested that critical data is anything that must be verified before transplant can occur, which are six data elements to be verified including organ type, blood type, donor ID, waitlist ID, laterality (if applicable).

EDM proposed the idea of having a standing DAC subcommittee that would work on existing data elements that need an overhaul, such as socioeconomic data, that would include a range of experts. Members were supportive of developing this standing subcommittee. EDM staff reminded the workgroup that the goal is to present this framework to the OPTN Board of Directors during their June 2023 meeting so it needs to be finalized in May 2023.

2. Workgroup Homework and Next Steps

EDM staff reviewed the 'Parking Lot' section of the spreadsheet. Members are asked to review, answer questions they are able to, and asking any questions they have. Members are asked to include their initials when answering another member's questions.

Upcoming Meeting

- November 4, 2022
- November 18, 2022
- December 9, 2022

Attendance

• Committee Members

- o Christine Maxmeister
- o Colleen O'Donnell-Flores
- o Karl Neumann
- o Rebecca Baranoff

• HRSA Representatives

o Adrianna Martinez

• SRTR Staff

- o Ajay Israni
- o Bert Kasiske

UNOS Staff

- o Brooke Chenault
- o Eric Messick
- o Janis Rosenberg
- o Kim Uccellini
- o Nadine Hoffman