

Meeting Summary

OPTN Data Advisory Committee
Holistic Data Review Workgroup
Meeting Summary
October 14, 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 10/14/2022 to discuss the following agenda items:

- 1. Welcome and Introductions of New Members
- 2. Revisit workgroup deliverables and timeline
- 3. Review Data Subject Areas
- 4. Workgroup Homework and Next Steps

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

1. Welcome and Introductions of New Members

Two new members joined the workgroup from the Transplant Coordinators Committee (TCC). The new, and existing members, introduced themselves and shared their background and connection the transplant. Enterprise Data Management (EDM) staff provided a brief overview of the project.

2. Revisit workgroup deliverables and timeline

EDM staff reviewed the workgroup deliverables and timeline for reporting to the Board of Directors. The workgroup deliverables are broken down into three categories: data, people, and sequencing. Data applies to documenting the scope of OPTN data, developing an inventory of data domains/subject areas, and identifying critical data elements. People refers to identifying the OPTN Committees who are responsible for these data domains, establishing responsibilities, and developing buy-in from all stakeholders. Sequencing includes assessing the current data risks, prioritizing data domains by risk level, recommending data review project sequencing, and determining if *OPTN Policy 18 Data submission Requirements* need modifying to close gaps contributing to data quality risk. The workgroup is working towards presenting the report during the June 2023 OPTN Board of Directors meeting.

3. Review Data Subject Areas

The workgroup reviewed data subject areas and discussed the trajectory of the group's work.

Summary of discussion:

Members discussed which data collection tools the workgroup would be working in. The OPTN Donor Data and Matching System (currently known as DonorNet®) and OPTN Waiting List (currently known as WaitlistSM) were identified as upstream systems since that is where the data originates and flows from. The OPTN Data System (currently known as TIEDI®) was identified as a downstream system since data will flow from the OPTN Donor Data and Matching System and the OPTN Waiting List into the OPTN Data System. However, all three of these systems are essential as they collect OPTN data that is in scope for a holistic review of data quality.

The workgroup discussed the importance of developing this framework and how it will continue to play an integral role in improving data quality throughout the OPTN. A member inquired about the public availability of forms once they are approved by the Office of Management and Budget (OMB). EDM staff will follow up with HRSA about this process and shared that the OPTN Waiting List will be sent to the OMB for approval next year.

4. 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

- October 25, 2022
- November 2, 2022
- November 18, 2022

Attendance

• Committee Members

- o Ashley Cardenas
- o Christine Maxmeister
- o Colleen O'Donnell-Flores
- o Jesse Schold
- o Karl Neumann
- o Krishnaraj Mahendraraj
- o Rebecca Baranoff

• HRSA Representatives

- o Adrianna Martinez
- SRTR Staff
 - o Bert Kasiske

UNOS Staff

- o Brooke Chenault
- o Eric Messick
- o Isaac Hager
- o Janis Rosenberg
- o Krissy Laurie
- o Laura Schmitt
- o Nadine Hoffman