OPTN Data Advisory Committee
Meeting Summary
April 22, 2024
Teleconference

Sumit Mohan, M.D, M.P.H., Chair
Jesse Schold, PhD., M.Stat., Vice Chair

Introduction

The OPTN Data Advisory Committee met via Webex teleconference on 04/22/2024 to discuss the following agenda items:

1. Review 24-month Refusal Code Monitoring report (final monitoring report)
2. Update regarding MPSC Referral – Transportation Events
3. HHS Directive update and next steps

The following is a summary of the (Sub)Committee's discussions.

1. Review 24-month Refusal Code Monitoring report (final monitoring report)

Review 24-month Refusal Code Monitoring report (final monitoring report) was re- scheduled for discussion at the OPTN Data Advisory Committee meeting on May 13, 2024.

2. Update regarding MPSC Referral – Transportation Events

The OPTN Contractor provided a status update regarding the MPSRC Referral – Transportation Events.

Data summary:

Recommendations were shared from the previous Data Advisory Committee meeting on 03/22/2024. The captured recommendations are shown here:

- Ensure representation from various regions and third-party transportation organizations involved in organ transportation.
- Understand what data third-party transportation providers are currently collecting. Implement a policy or requirement for the collection of transportation data to better understand successes, near misses, and issues during organ transportation.
- Address how to manage transportation data from third-party organizations that are not members of the OPTN (Organ Procurement and Transplantation Network).

Dependencies:

- Expeditious Task Force prioritizing Late Turndowns study and willingness to expand scope to include transportation data
- Operations and Safety Committee (OSC) agreement to form a workgroup and manage the study

The overall goal is improving the collection and management of transportation data related to organ transplantation, with a focus on involving relevant stakeholders, understanding current data collection practices, implementing data collection policies, and addressing challenges related to non-member organizations.

Summary of discussion:

The Chair suggested involving people with practical experience in organ logistics, such as administrators dealing with logistical challenges or coordinators who have had to turn down organs due to transportation issues. Their expertise would be valuable for the workgroup in addition to the OSC (Operations and Safety) members. A member drew a parallel to setting up the DTAC (Disease Transmission Advisory Committee) and expects the outputs to be similar. Another member shared that when working with EPIC (an electronic health records software vendor), they were unaware of the shift in responsibility related to developing an organ offer management documentation module. The same member recommends bringing this up with EPIC and other vendors like Cerner to ensure they are aware of these developments.

The main points are the importance of including subject matter experts with practical organ logistics experience, learning from previous similar efforts like DTAC's (Disease Transmission Advisory Committee) formation, and ensuring coordination with EHR vendors developing related software modules.

Call for additional Data Advisory Committee volunteers to join a potential OSC workgroup- three members volunteered.

Next steps:

Draft memo responding to MPSC with DAC's recommended path forward (April-May 2024)

3. **HHS Directive update and next steps**

The OPTN Contractor reviewed and discussed the HHS Directive update and next steps.

Data summary:

Proposed Pre-Waitlist Submission Methods:

- API (Application Programming Interface) - Transmitting data and validating it as part of the transmission process.
- Flat file or CSV file format - Uploading a file, which will be validated, and any rejected records will be returned for resubmission.
- Referral and Evaluation Forms - Manually completing and validating forms through a User Interface.

Draft Policy 18 Expectations for Pre-Waitlist Data:

- Referral and evaluation data forms are due quarterly, 30-day after the end of the calendar quarter. For example, Q1 2025 (January-March) data would need to be submitted by April 30, 2025, to be compliant. The data collection start date is yet to be determined and dependent on the release dates from the OPTN Contractor and Electronic Medical Record (EMR) Vendors.

In summary, these are draft proposals for methods to submit pre-waitlist data (API, file upload, manual forms) and a potential policy requiring quarterly submission of this data within 30-day after each quarter ends. The actual implementation timeline is still to be determined based on the readiness of the OPTN Contractor and EMR Vendors.

Summary of discussion:

The Chair reminded the members that the data elements recommended by the DAC Pre-Waitlist Workgroup will be posted for public comment as part of the OMB process. A OPTN contract member provided an update that they are working through finalizing the requirements for the ventilated patient form as well, which may impact some existing forms like the DDR and require deprecating certain forms.

This is still being discussed with HRSA and CMS. The 60-day OMB public comment period is anticipated to start sometime in May. The OPTN Contractor will draft a response incorporating feedback from the Data Advisory Committee, workgroups, and relevant committees like the Organ Procurement Organization Committee. This draft response will be shared with committees in advance.

There were suggestions made by the Vice Chair to facilitate a pilot program or have "early adopters" test out the data collection process to identify any issues before full implementation. An OPTN Contractor staff member mentioned this could be explored further with HRSA and vendors. A member raised concerns about some companies recently providing incorrect information about the data that would be collected as part of the directive. The same member suggested leveraging the OPTN contractor website and communications to provide accurate information to the community.

In conclusion, the Vice Chair proposed spearheading a pilot and developing tools/resources for transplant centers, which could make the process more tangible for stakeholders. The Chair suggested re-activating the pre-waitlist workgroup to share experiences, challenges, and solutions from those testing the data mapping process at their centers, which could improve data quality. Members volunteered to participate in testing the process for their respective EMR platforms like EPIC. The overall focus seemed to be on ensuring accurate information dissemination, facilitating early testing/piloting to identify issues, involving relevant stakeholders, and providing resources to support smooth implementation of the new data collection requirements.

Next steps:

None were discussed.

Upcoming Meeting(s)

- May 13, 2024 (Teleconference)
- June 10, 2024 (Teleconference)

Attendance

- **Committee Members**
  - Sumit Mohan
  - Jesse Schold
  - Kate Giles
  - Michael Ison
  - Paul MacLennan
  - Michael Marvin
  - Christine Maxmeister
  - Jennifer Peattie
  - Julie Prigoff
  - Alicia Skeen
  - Allen Wagner
- **HRSA Representatives**
  - Adrianna Alvarez
  - Steve Kennan
- **SRTR Staff**
  - Avery Cook
  - Ajay Israni
  - Jon Snyder
- **UNOS Staff**
  - Brooke Chenault
  - Huong Cunningham
  - Viktoria Filatova
  - Cole Fox
  - Nadine Hoffman
  - Sevgin Hunt
  - Sara Langham
  - Eric Messick
  - Lauren Mooney
  - Laura Schmitt
  - Holly Sobczak
  - Divya Yalgoori
  - Anne Zehner
- **Other**
  - Lisa McElroy
  - Ann McMillan