

**OPTN Data Advisory Committee
Meeting Summary
November 8, 2021
Conference Call**

**Rachel Patzer, MD, PhD, Chair
Sumit Mohan, MD, MPH, Vice Chair**

Introduction

The Data Advisory Committee (the Committee) met via Citrix GoToMeeting teleconference on 11/08/2021 to discuss the following agenda items:

1. Data Quality Report
2. Data Review Report

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

1. Data Quality Report

The Data Quality Report is an annual report presented to the Board of Directors. The report addresses the accuracy and applicability of OPTN data collected, and it was presented to the Committee for review. The Chair suggested that this report can help inform the Committee as to which projects should be considered for 2022.

Data summary:

Staff introduced the Data Quality Report by explaining its role in contract deliverables, noting that there are three main reports, the Data Quality Report, the Data Review Report, and the Data Advisory Committee Chair's report to the Board of Directors.

The report address three dimensions of data quality: Timeliness, Availability, and Accuracy

- Timely data submission
 - For Transplant Programs, whether forms are submitted by the due date, within 90 days of the due date
 - Predominantly forms are being submitted by the due date, with nearly all being submitted with 90 days of the due date
 - Exceptions to this are the Transplant Recipient Follow-Up form and the Living Donor Follow-Up form, which had approximately 71% submitted on time, and 83% submitted within 90 days of the due date
 - This was expected for 2020 as the amnesty policy granting transplant programs extra time to submit forms due to COVID-19 was in effect
 - Similarly, Organ Procurement Organizations (OPOs) are submitting nearly all forms (>90%) on time or within 90 days of the expected due date
 - When timely form submission rate was viewed from past years (2018, 2019, and 2020), transplant programs, OPOs, and histocompatibility labs were all improving or remaining constant in performance
- Dialysis data discrepancies
 - Dialysis status and start date are collected across multiple areas in the OPTN database

- This are sometimes discrepancies in this data, identified by Tsapepas et al (2020), which they noted based on analysis of the recorded days of the week, month, etc.
 - Center for Medicare and Medicaid Services (CMS) have a data dashboard which provides this information to transplant programs, but only 50 programs were using it
 - Staff mentioned this could be an area the Committee could focus on for education and data quality improvement
- COVID-19 Data Analysis
 - Some was highlighted in the last presentation to the Committee on the impact of COVID-19, but staff highlighted the percent of transplant recipient follow-up (TRF) forms that were ever in amnesty status and subsequently validated
 - There were initial concerns with the amnesty policy lowering the amount of data submitted to the OPTN by having forms in amnesty status never validated
 - Approximately 30% of TRF forms were ever in amnesty status at a given week, but with the amnesty policy ending on December 31, 2020, all forms that were not submitted were required to be validated
 - As of October 29, 2021, almost all TRF forms ever in amnesty status have been submitted
 - Staff noted this shows that policies can be implemented to help relieve the burden on programs during emergencies without a net loss of any data
 - A similar graph showed that living donor follow-up (LDF) forms, while having a slightly higher rate of falling into amnesty status, also were nearly 100% validated as of October 29, 2021
- Reporting of Unknown, Missing, or Not Done Values
 - Staff highlighted the data-locked preview report and the data lock dashboard, which could help programs identify where data may be missing in their system
 - These are part of the data lock policy, which has not yet been implemented, but the tools are still available for programs to use
 - These reports were accessed in 2020 by 137 and 115 centers for the data lock dashboard and the data lock preview report, respectively
 - Certain fields within TIEDI have a higher percentage of being unknown or missing values, which lowers data quality
 - These fields could benefit from re-evaluation by the Committee as to why they are often not completed or whether the information gathered is relevant and should be addressed
 - These fields were broken down by organ type, with most fields, staff noted, not being above 5%
 - Staff also posed the question, what percentage of unknown responses is unacceptable from a data quality standpoint?
 - Particularly for the Transplant Candidate Registration form, within pancreas and kidney-pancreas there were three fields with high (20-30%) percentages of unknown or missing data, though none were required fields

Summary of discussion:

A member inquired whether the fields that are often being left empty (insulin duration of use, for kidney-pancreas and pancreas, were missing values 29% and 22% of the time, respectively) are requiring too much specificity. To this, the Vice-Chair noted that, because of their non-required status, the Committee should consider whether the fields should be required, or conversely whether they collect relevant information. Additionally, they mentioned that there should be instructions as to what should be done if the specificity of information is not available. The Chair agreed that instructions should clearly state what steps should be taken in the event the requested information is not available, in order to minimize missing data. Furthermore, while the Chair did note time limitations for this meeting, they requested the distribution of both reports so the Committee could review and return for the subsequent one with questions or comments on the full report.

The Committee also reviewed fields frequently left unknown or with missing values on the transplant recipient registration form, to which staff noted there was no significant trend, but it may be worthwhile to approach organ-specific committees to discuss the fields. This could provide the Committee with non-required fields that could be struck from reporting forms if the data is no longer deemed necessary, or the field is not providing useful data.

Staff also commented that, while reviewing the transplant recipient follow-up form, the “functional status” field frequently was left blank across organ types. Additionally, cognitive and development showed a similar trend of missing data across organ types.

Finally, while reviewing the living donor follow-up form, staff pointed out that a significant number of the fields left incomplete were non-required lab values, which they hypothesized could still be a reaction to the amnesty policy from 2020. However, in order to assess whether that is the case, more years would have to be examined going forward. A member did inquire whether that meant that the 2020 report was particularly bad, as, anecdotally, they remembered the living donor follow-up form field completion being relatively poor. Staff stated that the dataset that was being reviewed was actually from the data lock dashboard tools, so prior to this report, the data set did not exist.

Next steps:

The Committee will continue discussion of the Data Quality Report and in particular how the Committee should address missing or incomplete data on a future call.

2. Data Review Report

This report summarizes the progress of the Committee over the past year and is subdivided into three broad categories: Purview over data-centric OPTN policies; Activities to Date; and Future Work. Additionally, it identifies how the Data Advisory Committee has acted as stewards of OPTN data.

Data summary:

- The report begins by reviewing the activities to date, which are as follows:
 - Implementation of *Modify Data Submission Policies (“Data Lock”)* delayed due to COVID-19 pandemic
 - Currently this project is pending Office of Management and Budget (OMB) approval, anticipated implementation spring 2022
 - Data quality tools developed to support members released 09/09/2020
- The report also addresses the future work of the Data Advisory Committee, specifically addressing how the Committee has considered:
 - Data submission compliance rates

- Frequency of data changing following submission, as well as the associated reason for the change
- Other relevant information identified by the Committee
- Recommendations to Improve Data
 - Review performance standards
 - The Committee is charged with adding, modifying, and removing data elements that it deems necessary
 - The Committee also reviewed activities to date on clarifying existing data definitions and creating new data definitions and how these should guide ongoing efforts to improve and standardize data collection
- Summary of OPTN data additions and modifications
 - Approximately 50% of policies pending board approval in December of 2021 impacted data
 - Of the policies that impacted data, 50% of all those approved or being considered in 2021 added data elements, 30% removed data elements, and 20% modified existing data elements

Summary of discussion:

Staff concluded the summary of the data by requesting two volunteers from the Committee to join a workgroup with the Transplant Coordinators Committee to review the relevancy of data elements.

Next steps:

The Committee will consider the Data Review Report and return with questions or comments to the subsequent meeting. Additionally, the Data Advisory Committee/Transplant Coordinators Committee workgroup requested two volunteers from the Committee to meet quarterly in review of data definitions.

Upcoming Meeting

- December 13, 2021

Attendance

- **Committee Members**
 - Rachel Patzer
 - Sumit Mohan
 - Kristine Browning
 - Jamie Bucio
 - Colleen Flores
 - Heather Hickland
 - Lauren Kearns
 - Macey Levan
 - Krishnaraj Mahendraraj
 - Melissa McQueen
 - Anna Mello
 - Alicia Redden
 - Benjamin Schleich
 - Daniel Stanton
 - Farhan Zafar
- **HRSA Representatives**
 - Shannon Dunne
 - Adriana Martinez
- **SRTR Staff**
 - Ajay Israni
 - Bert Kasiske
 - Jon Snyder
- **UNOS Staff**
 - Kristine Althaus
 - Brooke Chenault
 - Julie Coriaty
 - Abby Fox
 - Isaac Hager
 - Lauren Mauk
 - Maureen McBride
 - Samantha Noreen
 - Sarah Payamps
 - Matthew Prentice
 - Shannon Shepherd
 - Leah Slife
 - Susan Tlusty
 - Kimberly Uccellini
- **Other Attendees**
 - Elizabeth Boehnlein