

**OPTN Data Advisory Committee
Meeting Summary
October 21, 2024
Conference Call**

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Introduction

The OPTN Data Advisory Committee (the Committee) met via WebEx teleconference on 10/21/2024 to discuss the following agenda items:

1. Welcome, Reminders, and Agenda Review
2. Request for Committee feedback on using publicly available Social Determinants of Health (SDOH) in policy monitoring and evaluation
3. Review Annual Data Review Report
4. Highlights from Annual Data Quality Report: Results of analysis of Changes to Fields After Data Lock
5. Preview key information addressed in annual presentation to the OPTN Board: Highlights from Annual Data Review Report and Annual Data Quality Report
6. Open Forum
7. Closing Remarks

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

1. Welcome, Reminders, and Agenda Review

The Chair welcomed the members to the meeting. They were reminded that the meeting time was extended by 30 minutes in order to accommodate the discussion items. The Committee provided feedback regarding potential sources of Social Determinants of Health (SDOH) that could be helpful in monitoring and evaluating OPTN policies, bylaws, and activities. The Committee also received presentations regarding the annual deliverables to the OPTN Board of Directors. Members provided feedback concerning the prepared materials and shared their ideas for additional consideration. There were no requests to speak during Open Forum. The Chair provided closing remarks.

2. Request for Committee feedback on using publicly available Social Determinants of Health (SDOH) in policy monitoring and evaluation

HRSA directed the OPTN to work with the OPTN Data Advisory, Minority Affairs, and Patient Affairs committees to identify relevant public SDOH data sources for integrating into OPTN policy monitoring and evaluation activities. HRSA also directed that the committees' recommendations be consolidated in a report that is submitted to HRSA by the end of calendar year 2024. The presentation represents OPTN contractor staff's efforts to gather DAC members' input.

Summary of discussion:

No decisions were made as part of this agenda item.

SDOH are considered to be conditions in the environments where people live, work, and age that affect a wide range of quality-of-life and health outcomes. Such conditions are grouped into domains such as economic stability, education, health and health care, neighborhood and built environment, and social and community context.

The OPTN was directed by HRSA to identify relevant public SDOH data sources for integrating into OPTN policy monitoring and evaluation activities. OPTN contractor staff are seeking feedback from this Committee, the OPTN Minority Affairs Committee, and the OPTN Patient Affairs Committee. HRSA also directed the OPTN to consolidate the committees' recommendations in a report and submit the report to HRSA by the end of calendar year 2024. The intention is that SDOH data will be used as part of the policy monitoring starting in calendar year 2025.

The presentation represents OPTN contractor staff's efforts to gather input from the Committee about which data sources would be helpful for monitoring and evaluation purposes and to consider additional data sources. Contractor staff identified two goals for the SDOH project. First, assessing which public sources provide data that are most relevant and available for linking to OPTN data for the purposes of policy monitoring. Second, integrating public sources of SDOH data into policy monitoring to support OPTN committee efforts to assess equity in the system.

OPTN contractor staff presented overviews of several publicly available SDOH datasets for Committee consideration. The datasets described included the American Community Survey (ACS), the Agency for Healthcare Research and Quality (AHRQ) Social Determinants of Health Database, CDC's PLACES, USDA's Rural-Urban Commuting Areas Codes, as well as two indices, the Area Deprivation Index (ADI) and the Social Deprivation Index (SDI).

Committee members provided feedback about the appropriateness of the identified SDOH datasets. Members also suggested additional selection criteria OPTN contractor staff may want to consider when selecting the datasets. The Chair told OPTN contractor staff to consider the level of geographic detail needed for area-level social determinants of health and the implications and shortcomings associated with using just a five-digit zip code. Committee members supported the Chair's comments and indicated that adding individual-level address information would be ideal for a better and more specific understanding of social determinants of health information. Members recommended considering the limitations of using zip codes as a level of analysis for the merged data sets. The concordance between area-level deprivation indices varies, so careful selection of diverse composite descriptors is important. As part of the selection process, OPTN contractor staff were told to review the project goals and consider careful selection of area-level deprivation indices, including two that are not highly concordant. Because of the variation among indices, it was suggested that individual level social determinants of health should be considered to tell a more complete story. For example, when determining which dataset or datasets to include, the selection process should consider including population-level measures of mortality related to liver disease for a more comprehensive understanding of access to transplantation. Committee members also suggested contractor staff should plan ahead for dealing with potential data discrepancies when using different data sources or indices. A patient representative on the Committee asked if the intention is to add the SDOH data to the OPTN data registry? OPTN contractor staff responded that the intention is not to add the SDOH data to the OPTN registry; rather, the data will be matched or merged with zip code level data for the purposes of adding information to the monitoring reports following policy implementation.

The Chair stated that the SDOH data are critical for understanding how they impact processes of patient care and patient outcomes. He also said that the importance of the data will likely be magnified when the pre-waitlist data are fully part of the OPTN data registry. The SDOH information will be helpful for explaining variation in patient outcomes but also for identifying disparities and barriers to care.

A patient representative on the Committee highlighted the importance of patient-level data versus higher level of zip code data. The member said that from the patient perspective, economic stability for pre-waitlisting is a very important consideration. The member added that economic stability is a crucial indicator about a patient’s ability to afford the transplant after surgery, based on purchasing medications, and attending doctor and other appointments, for example.

Next steps:

OPTN contractor staff thanked the members for their input. Contractor staff acknowledged the Committee’s concerns about the limitations associated with performing analyses at the zip code-level, instead of a more specific geographic measure.

3. Review Annual Data Review Report

Discussion of this agenda item was combined with that of the agenda item “Preview key information addressed in annual presentation to the OPTN Board: Highlights from Annual Data Review Report and Annual Data Quality Report.”

Summary of discussion:

No decisions were made as part of this agenda item.

Next steps:

Not applicable.

4. Highlights from Annual Data Quality Report: Results of analysis of Changes to Fields After Data Lock

OPTN contractor staff provided an overview of the results associated with an analysis of changes made to OPTN data after the submission deadlines for the data had passed.

Summary of discussion:

No decisions were made as part of this agenda item.

OPTN contractor staff provided results from an analysis of the data unlocking activities of OPTN members. Specifically, the analysis focused on identifying the information OPTN members are changing when a TIEDI® form is unlocked. To perform the analysis, contractor staff created a process to count the number of changes to a field after the field’s form is locked. The analysis included around 1,500 fields in the review, which covered the period from September 1, 2022 through September 1, 2024. The analysis looked at data changes involving changing an existing value to a new value and from null value to a value. The analysis also captured whether the changed fields were on forms that had been submitted late (after the submission deadline) or validated after the expected date. That part of the analysis likely identifies cases where a form was filled out after the expected date and data was being entered into that field for the first time—indicating a change from a null value to a value.

The analysis results suggest that the majority of changes occurred on forms that were submitted late, likely indicating the data were being submitted for the first time. Additionally, while some of the data being changed represent values that are used in the SRTR contractor’s Program Specific Reports (PSR),

there appears to be an even split in terms of the number of changes across data elements capturing demographic values, clinical values, and PSR-specific values.

Missing data on the Transplant Recipient Follow-up (TRF) form is different than missing on the Transplant Candidate Registration (TCR) or Transplant Recipient Registration (TRR) forms because there is more justification for finding and/or obtaining the data later after a follow-up visit. In addition, the results might also suggest that the 'date of discharge' is often left blank on the TRR form, and then filled in later on the six-month TRF form. A member suggested evaluating the need for specific data fields on the TRF and determining which, if any, could be eliminated.

Committee members offered the following suggestions. When considering future changes to the data lock requirements of Policy 18, the Committee and the OPTN Board of Directors (Board) should consider the challenges transplant programs experience with delayed reporting due to staff resources when adding new data collection projects. For instance, the members discussed Medicare reimbursement practices for transplant-related activities. It was stated that the Medicare cost report does not cover post-transplant resources at the program-level, leading to a significant amount of OPTN data collection forms that need completion but for which there are few resources. Other Committee members said that transplant programs can charge a significant portion of their quality team to the Medicare cost report.

Members also said that the Committee should provide members' thoughts on amending OPTN Policy 18 concerning extending the established submission deadlines established and managing the growing volume of reportable OPTN data. The Committee expressed concern about the impact on OPTN members. A member added that there is a need for clearer definitions and ongoing evaluation of data elements to ensure their relevance and value. In terms of an ongoing evaluation, it was recommended that there should be a review of current fields on each form and that a clear rationale should be provided for the inclusion of each data field in the OPTN data registry.

The members indicated their interest in working with the Board to develop data standards and improve data usability. OPTN contractor staff reminded them that any projects for improvements would need to go through a structured process and may not be implemented until next year.

Next steps:

OPTN contractor staff indicated that the Committee did not have to make a decision right away about pursuing additional facets of the data analysis. Rather, the Committee should focus on the annual deliverables in the short-term. To that end, the OPTN contractor staff asked for Committee members to share their ideas about improving data quality within the next few weeks so that the ideas can be incorporated in the presentation to the OPTN Board.

5. Preview key information addressed in annual presentation to the OPTN Board: Highlights from Annual Data Review Report and Annual Data Quality Report

A summary of the findings and recommendations contained in the Annual Data Quality report, the Annual Data Review report, and the Chair's annual presentation to the Board was provided to the Committee members. Members discussed the findings and recommendations and shared additional ideas for potential inclusion in the materials.

Summary of discussion:

Decision #1: The Committee decided on highlighting certain aspects of data collection in their report to the OPTN Board, such as the importance of collecting relevant data and eliminating the collection
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of irrelevant data. The members also identified strengthening their engagement with the OPTN Board as it pertains to improving data collection and making data more actionable.

A member pointed out that OPTN members are indicating that a lack of staffing resources is the primary reason for unlocking data; however, the OPTN continues adding data fields for collection and reporting without addressing the existing resource limitations. The Committee member added that perhaps the OPTN should assess the resources needed to support data reporting and abstraction from the perspectives of transplant programs, OPOs, and histocompatibility laboratories.

Another member said that there is a need for clearer data definitions and ongoing evaluation of data elements to ensure their relevance and value. The member said that there are multiple data elements where it is unclear why the information is collected or who is using it. As a result, there should be a review of current data fields on each collection form and a clear rationale provided for their inclusion. Performing such an undertaking, the member continued, requires ownership of the data elements, definitions, etc. DAC should identify a deadline for such data owners to provide definitions of their data elements and to justify why the data fields should continue to be collected. That would greatly assist with eliminating unnecessary data collection and improving efficiency. The so-called data owners could also be responsible for identifying a funding source when collection of new data elements is requested to assist the entities performing the collection and reporting. A member concurred with this idea. The member said that a good example involves reporting whether a patient is on a generic product or a brand name product on the TRF (and possibly the TRR). Reporting is required for all organ-types. The member stated that it is unclear who uses that information and for what purposes. They concluded that the data element would be appropriate for removal from the collection forms. A member suggested that the Committee could make a formal recommendation that unless data elements on the TRF are needed as part of SRTR's PSRs, then the data element will be eliminated unless the data owner provides a justification as to why the information should continue to be collected. Another option could be to eliminate follow-up data collection to three or five years, with nothing be collected beyond five-years post-transplant. Another member agreed and questioned the value of the information after five years. The members agreed that such a recommendation would not apply to events involving deaths and graft loss. Others also cautioned that eliminating data fields needs to be pursued thoughtfully and cautiously within the goal of creating a better data registry. The Chair agreed and added that the Committee should focus on being more nimble in order to replace data that are no longer relevant with more salient data in a much more expedient fashion. The Chair added that the cadence of eliminating and adding data is something the Committee should be involved with more closely, as well as ways to perform such a function in a more efficient way.

OPTN contractor staff said that the OPTN strategic plan identifies the need to make OPTN data more actionable. However, it is not perfectly clear what "actionable" means in context. As a result, the Committee might want to ask for greater engagement with the OPTN Board in order to clarify whether the Board's intention was for DAC to be more involved with making data more actionable. The Vice Chair suggested explaining that the Committee is very eager to work with the Board to help develop data standards.

Next steps:

OPTN contractor staff will take the comments provided during the meeting and integrate them in the Chair's presentation to the Board, as appropriate. The Chair will go through the presentation with the Committee as part of the 11/18/2024 meeting.

6. Open Forum

No requests from the public to address the Committee during open forum had been received.

7. Closing Remarks

Committee members were encouraged to submit additional questions and ideas concerning the topics addressed in the Board presentation and the Data Quality and Data Review reports to OPTN contractor staff as soon as possible in order for the information to be considered for inclusion.

Upcoming Meetings (Meetings start at 3:00 pm (ET) unless otherwise noted)

- ~~July 8, 2024~~
- ~~August 12, 2024~~
- ~~September 10, 2024 – In-person meeting, Detroit, MI, 8:00 am – 3:00 pm (ET)~~
- ~~October 21, 2024~~
- November 18, 2024
- December 9, 2024
- January 12, 2025
- February 10, 2025
- March 10, 2025
- April 14, 2025
- May 12, 2025
- June 9, 2025

Attendance

- **Committee Members**
 - Jesse Schold
 - Lisa McElroy
 - Rebecca Baranoff
 - Kate Giles
 - Cassie Hertert
 - Paul MacLennan
 - Michael Marvin
 - Christine Maxmeister
 - Nancy McMillan
 - Sumit Mohan
 - Jennifer Peattie
 - Julie Prigoff
 - Meghan Schaub
 - Lindsay Smith
 - Allen Wagner
- **HRSA Representatives**
 - Adriana Alvarez
 - Steve Kennan
- **SRTR Staff**
 - Avery Cook
 - Allyson Hart
 - Jon Miller
 - Jon Snyder
- **UNOS Staff**
 - Brooke Chenault
 - Jonathan Chiep
 - Cole Fox
 - Michael Hollister
 - Eric Messick
 - Lauren Mooney
 - Tatenda Mupfudze
 - Nadine Rogers
 - Laura Schmitt
 - Sara Rose Wells
- **Other Attendees**
 - [None]