

**OPTN Data Advisory Committee  
Meeting Summary  
January 13, 2025  
Conference Call**

**Jesse Schold, PhD., M.Stat., M.Ed.  
Lisa McElroy, MD, MS, FACS**

## **Introduction**

The OPTN Data Advisory Committee (the Committee) met via WebEx teleconference on 01/13/2025 to discuss the following agenda items:

1. Welcome and agenda review
2. Status updates
3. Review and consideration of 2025 DAC priorities
4. Public Forum
5. Closing Remarks

The meeting discussed updates, potential policy changes, and the need for improved data quality and standardization in the field of organ transplantation. The following is a summary of the Committee's discussions.

### **1. Welcome and agenda review**

The Committee Chair welcomed the attendees. OPTN contractor staff provided an overview of the agenda items, which included updates regarding the Committee's past work and potential follow-up activities resulting from that work. The members were told that the OPTN public comment period will open on 01/21/2025 and close on 03/19/2025. A hyperlink was provided to help members access the policy proposals, request for feedback documents, and other materials when public comment opens on 01/21. Members were also informed that the OPTN regional meetings will start on 01/28, and a hyperlink was provided to help them register for the regional meetings ahead of time.

### **2. Status updates**

An update was provided about the next steps stemming from the 11/21/2024 presentation of the Committee's annual deliverables to the OPTN Board of Directors (Board). The members were also updated on the status of the HHS Data Directive.

#### Summary of discussion:

No final decisions were made as part of this discussion.

OPTN contractor staff discussed the briefing paper being drafted for the Board. The paper is intended to document the Board's recommendations and requests that were discussed during the 11/21/2024 meeting, such as the creation of an OPTN data champion role on the Board. Contractor staff also said that, to their knowledge, no Board members have expressed an interest in serving as data champion.

As for the HHS Data Directive, OPTN contractor staff revisited the timeline of previous events. Following submission of the OPTN's formal response to HRSA, the OPTN President emailed the community alerting

them that response was available on the OPTN website. The public comment period associated with HRSA's 60-day Federal Register Notice ended on 01/03/2025. HRSA will review the submitted comments and determine if changes are warranted to the data collection forms as they appeared on the Federal Register. The next step will be for HRSA to publish the 30-day notice on the Federal Register, and while no formal dates have been provided, HRSA staff have suggested it could happen sometime in the spring of 2025.

Next steps:

The Chair and OPTN contractor staff said that more information will be provided as it becomes available.

**3. Review and consideration of 2025 DAC priorities**

The Committee reviewed the list of 16 potential action items they developed during their 09/10/2024 in-person meeting. The list was recently updated to identify actions the Committee could take alone or through collaboration with other entities. The members discussed adding more activities to those identified.

Summary of discussion:

No final decisions were made as part of this discussion.

The Chair told the members that for this discussion they should think about what the Committee's priorities should be, with a particular focus on those items that that could be addressed by the Committee with a relatively low level of effort. The Chair also mentioned that some of the bigger ideas they have identified would likely require collaboration with other OPTN committees and other entities. The Chair said that there are items on the list that the Committee should discuss because they could be addressed in the near future. The Chair also acknowledged that some of the items will most certainly require additional resources which may or may not be available when the Committee wants to work on them. OPTN contractor staff pointed out that in addition to new activities, the Committee also has its supply of regular activities, such as reviewing other OPTN committees' data collection projects and developing the annual Board deliverables.

OPTN contractor staff went through the list of potential action items and identified the extent to which the items could be performed by the Committee acting alone or other entities would need to be involved.

Committee members identified the need to expedite implementation of OPTN data changes and explore alternative pathways to the current OMB process. Members were reminded that the OPTN President and immediate past President were interested in this idea as a potential overall process improvement. The Chair mentioned that their Data Directive work might make the Committee well-suited to lead this effort on behalf of the OPTN.

One of the potential action items focuses on improving data quality by enhancing Application Programming Interface (API) functionality and partnering with internal staff and external vendors. Committee members asked OPTN contractor staff to inquire about availability and interest in enhancing API functionality. A member encouraged initiating conversations and obtaining commitments from the vendor EPIC regarding the development of functional APIs for the transplant community. There was also a request to advocate for standardization of APIs across all organizations to improve data capture and reduce the data burden. Another member said that there needs to be standardization across all the

OPTN members when it comes to APIs. The Committee member added that some organizations are able to capture more information than others, and creating something that will bring all organizations up to the same level would be helpful and reduce data burden.

The Committee also considered potential action items that would likely result in OPTN policy changes. For example, updating *Policy 18: Data Submission Requirements* to place responsibility for certain data quality and data consistency actions on committees and/or implementing data auditing actions could be an option the Committee wishes to pursue. The Committee could also make changes to *Policy 18* modifying the functioning of the “data lock.” The Committee has received a lot of analyses about the results of the lock and it remains very loose, the Chair said, before adding that the Committee should make a decision about how it wants to evolve the data lock, rather than continuing to observe it for another year. The Chair expressed his support for making the data lock more stringent. The Chair said that making the data lock more stringent could align with some of the other potential action items identified on the list. For instance, the Committee has observed that the data lock may be more appropriate for certain data fields versus others. Specifically, the Committee has previously agreed that they would be less sympathetic to allowing transplant programs to change data found on the Transplant Candidate Registration (TCR) and Transplant Recipient Registration (TRR) forms than they would be to changes made to the Transplant Recipient Follow-up (TRF) forms, where there is clearly a lot of variation in data reporting. So, the Committee could consider leading a project to address a combination of identified issues, according to the Chair.

Another potential action item involves reviewing the causes, mechanisms, and circumstances of death that are included on the Deceased Donor Registration (DDR) form. The Committee started working on this as a project in 2023 but had to pause the project in order to focus on addressing the HHS Data Directive. A lot of background work has already been completed for the project so the Committee would not be starting from scratch. Changes could improve consistency with data collection and reporting currently performed by the U.S. Centers for Disease Control and other sources, such as state health departments.

The members were asked for feedback on prioritizing and championing these actions. OPTN contractor staff pointed out that policy projects involve multiple steps, such as developing project forms, obtaining information technology (IT) resource estimates, and submitting information to the OPTN Policy Oversight Committee for approval to work on a project. They also require developing a public comment proposal and board briefing paper to move activities forward.

The members considered the advantages and disadvantages of defining critical OPTN data fields, establishing an audit program around those fields, and potentially removing non-critical data fields. Members discussed how the Committee might start identifying what qualifies as critical OPTN data. A members asked if it is possible to identify the OPTN data fields that are used most often as a way to focus any future efforts, rather than starting with a blanket approach like asking committees “what data are important to you?” Another member asked if there is a way to determine when data fields were added to the OPTN registry? From that information, the Committee could consider how often the field is used or not used, how many times it has been changed, etc., as a way to narrow down the list of critical data for consideration.

The Committee talked about the OPTN community’s lack of understanding about the importance of data quality and how it creates a barrier to improved data quality, but one that can be addressed with a low

level of effort. It was mentioned that the Committee might want to consider creating educational materials or documenting best practices and sharing that information with the OPTN community. This could include describing what data is collected, why those data fields are important, and sharing examples of how it is collected and reported effectively and efficiently so that OPTN members have a better understanding of why the information is important and what is expected of them. A Committee member mentioned that DAC could successfully develop educational materials without needing a lot of involvement from other OPTN committees, so such an effort could have a high impact while only needing a low level of effort. The Vice Chair stated that while the field of data science is rapidly evolving, it is fairly established. As a result, the Committee could play an important role within the OPTN by distilling complex, technical information into language that is more accessible for all OPTN members.

The Committee also talked about undertaking an effort to reduce the inclusion and use of “other, specify” as a response option within the OPTN data registry. The Committee had previously identified three areas for consideration where “other, specify” is a valid response option and how it almost becomes a default option for OPTN members to use. The Chair suggested asking Committee members to pair-up in small groups to specifically review the data fields in question and propose new response options that could replace the use of “other, specify.” The Chair noted that previous analyses of “other, specify” have identified common themes based on what OPTN members report and those themes could be added as new response options. The Chair proposed having groups of Committee members review each of the three potential action items associated with “other, specify” and identify new response options that could be used instead. Those initial ideas could then be shared with the full Committee to review and to consider whether the proposed options adequately address all possibilities, including whether “other, specify” must be maintained. The Chair added that such an effort would add to the quality of OPTN data, especially when it involves those data elements that are viewed as fairly important. The effort could be done in concert with some of the bigger ideas the Committee has identified and would add value again to the quality of the data. The effort could be pursued without requiring other OPTN committees to do a lot of work that may not align with those committees current interests.

The Committee discussed how developing consistency in death tracking and dialysis data is a priority for improved outcomes and understanding patient access to transplant. A previously identified activity involves exploring the possibility of restarting or creating new agreements for access to U.S. Centers for Medicare & Medicaid Services (CMS) data.

A Committee member asked about potentially creating an OPTN data report for each transplant program that identifies all patients who have ever been waitlisted or transplanted at the program and the death dates of all such patients, where such information exists. The timeframe of the reporting should go back as far as possible, according to the Committee member. If the OPTN can provide such information, then programs can update their records which will lead to a clearer picture of how well the entire OPTN transplantation process is working for patients. The member said that this is similar to the reasons why the HHS Data Directive added pre-waitlist information for collection, to better understand the management of care from the beginning to the end of the transplantation process.

Along those lines, the Committee also discussed creating a transplant-specific data standard through the U.S. Office of the National Coordinator for Health Information Technology (ONC) that would provide a

national mechanism for implementing and standardizing transplantation-related data among all hospitals participating in Medicare.

The Committee discussed the need to explore acquisition of CMS data. This will require exploring the possibility of restarting or creating new agreements for access to CMS data. The Chair said the lack of such agreements currently manifests itself in different pieces of the process. For example, the OPTN collects the pre-transplant dialysis date, which provides information about candidates prior to their receiving a transplant on the kidney transplant waiting list. Discrepancies have been identified between the information provided by centers and the information CMS has. This also ties back to one of the earlier points about post-transplant return to dialysis and/or graft failure data. While such information is in the federal data systems, it is not shared cohesively to make all those consistent with the OPTN's processes. The Chair added that the information being discussed is fundamental to understanding access to transplant and patient outcomes, and that the Committee should consider this a very high priority and it is something that is very doable by just aligning all of the data sources.

Next steps:

Committee members were asked to email additional project suggestions and/or comments about the potential action items to OPTN contractor staff and to copy Committee leadership on the emails. OPTN contractor staff will compile the feedback for sharing at a future meeting.

#### **4. Public Forum**

No requests from the public were received prior to the meeting to address the Committee during open forum.

#### **5. Closing Remarks**

The Chair let the members know that potential dates in March for an in-person meeting are being explored. More information will be forthcoming.

#### **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 4, 2024 10:30 am – 2:30 pm (ET) – HHS Data Collection Directive Meeting~~
- ~~December 9, 2024 11:00 am (ET)~~
- January 13, 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
  - Cassie Hertert
  - Michael Ison
  - Paul MacLennan
  - Michael Marvin
  - Christine Maxmeister
  - Jennifer Peattie
  - Julie Prigoff
  - Alicia Skeen
  - Lindsay Smith
  - Allen Wagner
- **HRSA Representatives**
  - None
- **SRTR Staff**
  - Avery Cook
  - Ryo Hirose
  - Jon Miller
- **UNOS Staff**
  - Brooke Chenault
  - Jonathan Chiep
  - Cole Fox
  - Jesse Howell
  - Eric Messick
  - Lauren Mooney
  - Sara Rose Wells
- **Other Attendees**
  - None