

**OPTN Data Advisory Committee**

**Meeting Summary**

**April 10, 2023**

**Conference Call**

**Sumit Mohan, MD, MPH, Chair**  
**Jesse Schold, PhD, M.Stat, M.Ed, Vice Chair**

**Introduction**

The Data Advisory Committee (DAC) met via Citrix GoToMeeting teleconference on 04/10/2023 to discuss the following agenda items:

1. 6-Month monitoring report of *Modify Data Submission Policies* project
2. Modification to data collection for *Improving Liver Allocation: MELD, PELD, Status 1A and Status 1B*
3. Committee members' discussion of experiences serving on OPTN Workgroups
4. Data definition consent agenda: Viral Detection

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

**1. Check-6-Month monitoring report of *Modify Data Submission Policies* project**

The DAC reviewed a 6-month monitoring report of the *Modify Data Submission Policies* project.

Data summary:

In summary, this six-month post-implementation monitoring report on data accumulated to date following the Updates to Policy 18, Data Submission Requirements project found the following general data trends:

- Following the implementation of the 30- or 60-day increases to eight OPTN Data Collection System forms in this policy change, national timely form completion rates rose for all forms
- Timely completion rate increases were highest for histocompatibility forms submitted by labs (i.e. RHS and DHS), and seven of the eight forms have national timely completion rates above 90% post-policy, compared to only one pre-policy. Two of the eight now have timely completion rates above 95%, compared to only one pre-policy.
- The most frequently unlocked form was the TRF. As each recipient has multiple TRF forms generated over the course of their follow up, and as post-transplant follow-up can present challenges for programs, this is not unexpected.
- Form-level unlocking volume was highly variable by week. There was, however, a notable spike in TCR and TRR unlocking activity in late October, potentially corresponding with the data review period that precedes the release of updated transplant program performance monitoring.
- Reasons given for unlocking activity were also highly variable by week. The same spike in TCR and TRR unlocking noted above occurs roughly at the same time that a spike in unlocking attributed to "Internal auditing results" occurs.
- The most common reason given for unlocking a form over the entire period, however, was "Delayed reporting due to staff resource issues". This speaks to concerns members have reported about having enough staff capacity to maintain timely data entry policy compliance. As

the OPTN must routinely weigh data entry burden against the need for adding data elements to existing data collection, this common reason for delayed edits to OPTN data should be considered in future discussions of data quality.

Summary of discussion:

The Vice Chair asked if there are analyses to understand whether the policy is attenuating unneeded data changes. Research Staff responded that there will be upcoming analyses to review specific data element changes pre and post implementation of the *Modify Data Submission Policies* project.

A member noted that they have received feedback that the data lock dashboard is overwhelming and there may be a lack of understanding on how to incorporate that tool into practice. Staff requested for DAC members to share any feedback regarding the data lock dashboard in order to make appropriate improvements to ensure utilization of the tool.

The Chair noted that there is a lot of data change around the time that SRTR provides secure site reviews. The Chair asked for SRTR's input on how they plan to move forward with review documents that encourage data review given the *Modify Data Submission Policies* project intent to prevent constant data change. An SRTR representative stated that this may be a learning process and more granular analysis would be helpful to determine an appropriate solution.

The Chair asked if there is an audit plan to identify the transplant programs that are frequently unlocking data to change and understand what is prompting these outliers. Another member responded that auditing is important, however, transplant programs are going to spend their limited resources on the data that impacts metrics. The Chair agreed and added that if there is a lot of change in data related to metrics, it raises questions about the quality of reporting for all OPTN data.

The Vice Chair noted that the intent of the policy was to attenuate easily manipulated data. The Vice Chair explained that it is important to understand whether the policy is meeting that objective.

A member asked if the monitoring report can analyze specific form detail within the Transplant Recipient Follow-up (TRF) form, such as comparing one-year follow-up and 5-year follow-up to see if there are trends for specific types of forms. Research staff responded they will follow-up with the DAC on this request.

Next steps:

The Committee will continue to discuss and review monitoring reports related to the *Modify Data Submission Policies* project.

**2. Modification to data collection for *Improving Liver Allocation: MELD, PELD, Status 1A and Status 1B***

The DAC reviewed a data collection modification from the OPTN Liver & Intestinal Organ Transplantation Committee regarding their project, *Improving Liver Allocation: MELD, PELD, Status 1A and Status 1B*. Based on feedback from subject matter experts, the OPTN Liver & Intestinal Organ Transplantation Committee is proposing to change the label for the data element of "current sex" to "sex for purposes of adult MELD calculation" and update definition.

Summary of discussion:

A member asked for information on the plan for electronic health records (EHR) vendors to be able to map this new data element. Staff responded "sex for purposes of adult MELD calculation" will be retrieveable by API but not updated.

Another member asked whether the OPTN Liver & Intestinal Organ Transplantation Committee considered utilizing review boards to address instances of transgender liver candidates. Staff responded that the OPTN Liver & Intestinal Organ Transplantation Committee did discuss that pathway but ultimately decided it was a decision for the candidate and transplant team to make.

The Chair asked if the OPTN Liver & Intestinal Organ Transplantation Committee considered using different ways to measure creatinine. Staff responded that the OPTN Liver & Intestinal Organ Transplantation Committee agreed to maintain the use of creatinine, but not incorporate a difference in creatinine measurement.

The DAC endorsed the updates to the data element.

Next steps:

The DAC's endorsement will be sent to the OPTN Liver & Intestinal Organ Transplantation Committee.

**3. Committee members discussion of experiences serving on OPTN Workgroups**

Members of the DAC reported their experiences serving on cross-committee workgroups.

Summary of discussion:

Members agreed that their cross-committee participation in workgroups is beneficial and rewarding. The Chair asked if the members serving on OPTN workgroups feel empowered to represent the DAC and express opinions about data collection. Members agreed and stated that participation in these workgroups are well worth their time. One member noted it has allowed for them to reach out to their colleagues and develop a greater understanding of the data workflow, processes, and barriers.

The Chair encouraged other DAC members not yet involved in cross-committee work to volunteer should they have the interest and time.

Next steps:

DAC members will continue to engage in OPTN workgroups and report out the experience and progress.

**4. Data definition consent agenda: Viral Detection**

The DAC reviewed a data definition clarification for *viral detection*.

Summary of discussion:

There were no comments or questions.

Next steps:

There was not quorum during this agenda item, so the DAC will vote on updates to the *viral detection* data definition via email.

**Upcoming Meetings**

- May 8, 2023 (teleconference)
- June 12, 2023 (teleconference)

## Attendance

- **Committee Members**
  - Daniel Stanton
  - Christine Maxmeister
  - Farhan Zafar
  - Jamie Bucio
  - Jesse Schold
  - Lauren Kearns
  - Macey Levan
  - Michael Marvin
  - Meghan Muldoon
  - Michael Ison
  - Paul MacLennan
  - Rachel Patzer
  - Rebecca Baranoff
  - Sumit Mohan
- **SRTR Staff**
  - Ajay Israni
  - Jon Snyder
- **UNOS Staff**
  - Ashley Woodards
  - Brooke Chenault
  - Eric Messick
  - Joel Newman
  - Kim Uccellini
  - Krissy Laurie
  - Laura Schmitt
  - Laura Cartwright
  - Lloyd Board
  - Matt Cafarella
  - Meghan McDermott
  - Michael Hollister
  - Nadine Hoffman
  - Sevgin Hunt
  - Suhuan Wang
  - Susan Tlusty
  - Taylor Livelli