

**OPTN Data Advisory Committee
Meeting Summary
March 7, 2022
Conference Call**

**Rachel Patzer, Ph.D, Chair
Sumit Mohan, M.D., M.P.H., Vice Chair**

Introduction

The Data Advisory Committee (the Committee) met via Citrix GoToMeeting teleconference on 03/07/2022 to discuss the following agenda items:

1. Announcements
2. Standardize Biopsy Collecting and Reporting – Public Comment Check In
3. Lung Updating Mortality Models – Second Check In
4. Holistic Approach to Data Collection – Check In

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

1. Announcements

Summary:

Ethics – Transparency in Program Selection

The Chair informed the Committee of an OPTN Ethics Committee sponsored white paper focusing on transparency in program selection. The white paper will comprise an ethical analysis of the need for transparent, accessible, patient-centered data to inform patient decision –making in transplant selection. The Ethics Committee is seeking volunteers from the Data Advisory Committee to assist in the development of the white paper.

Late Turndowns Memo

The Committee briefly discussed the memo that was drafted for the Policy Oversight Committee (POC) on late turndowns. The Committee had no questions on the draft and staff will be delivering the memo to the POC.

2. Standardize Biopsy Collecting and Reporting – Public Comment Check In

The Committee heard a presentation on the Kidney Committee’s proposals, Establish Minimum Kidney Donor Criteria to Require Biopsy and Standardize Kidney Biopsy Reporting and Data Collection. The full proposals, as well as public comment feedback, can be read on the [OPTN website](#).

Data summary:

Establish Minimum Kidney Donor Criteria to Require Biopsy

This proposal will identify a set minimum standard for when a kidney procurement biopsy must be performed. This does not impact a program’s ability to voluntarily perform a biopsy or biopsies beyond procurement biopsies.

Standardize Kidney Biopsy Reporting and Data Collection

This proposal will create a standard reporting form for information collected within a procurement biopsy.

Summary of discussion:

Staff responded to a question posed in the chat asking whether the information required by the reporting proposal would be required fields on the deceased donor registration (DDR); the proposed additions would be required fields if a biopsy was performed. The Vice Chair also inquired whether the biopsy workgroup had considered the Banff guidelines in developing the criteria required to be reported, and whether the workgroup had considered a field to indicate if the biopsy was adequate per those guidelines. The workgroup had reviewed the Banff guidelines and chose not to base the standardized report off them because they were created to standardize histological assessment in terms of organ viability, not to provide baseline graft characteristics. However, the workgroup did opt to include several parameters included in the Banff criteria. Furthermore, there is currently guidance published by the OPTN as to what constitutes an adequate sample, but the workgroup did not want to dictate requirements for an adequate sample.

The Vice Chair also asked whether there would be an area to determine who was reading the procurement biopsy. In the current proposal, staff responded, there is no area to determine it. The Vice Chair suggested that the form could include a field to indicate whether the person reading the biopsy had renal pathology experience.

Next steps:

The Kidney Workgroup will consider the Committee's feedback.

3. Lung Updating Mortality Models – Second Check In

The update to mortality models will update data fields used to calculate composite allocation scores (CAS) and collect new data that may identify trends in waitlist mortality and post-transplant survival. This data collection has the potential to inform future revisions to the CAS calculation.

Data summary:

The update will impact the CAS calculator, Waitlist, and Waitlist Reports.

The proposed data element revisions are:

- Adding a lung diagnosis code
- Diabetes
- Supplemental oxygen
- Assisted ventilation
- Minor reorganization of where fields are located for improved flow of data entry

The proposed data element additions are:

- Pulmonary hypertension fields
- Symptomatic fields
- Prior lung surgery
- Prior cardiac surgery
- Pleurodesis
- Microhistory
- Additional lab information

Summary of discussion:

The Chair voiced support for the proposed updates and additions, noting that it seemed well laid out. She also added that the proposed fields would need data definition updates as well. A second member supported the Chair's approval, contributing that it was thorough and had clarity to details. The Chair commented that, specifically for the diabetes field, any changes would need to be consistent across other organs. The presenter replied that diabetes may need to be collected differently across different organ types, as lung was primarily concerned with the prevalence of diabetes and its treatment, rather than the type. Staff clarified that, at present, diabetes information was already collected differently between the kidney transplant candidate referral (TCR) form and the lung fields.

Next steps:

The Lung Committee will coordinate with the Committee about public comment review when finalized into a proposal.

4. Holistic Approach to Data Collection

The Committee reviewed the National Academy of Sciences, Engineering, and Medicine (NASEM) report on more equitable transplant system. The report contains recommendations relevant to the work of the DAC and their holistic approach to data collection project.

Data summary:

The report was published in February 2022, and contained a series of recommendations surrounding the United States transplant network. Specifically relevant to the DAC was their recommendation to "Create a dashboard of standardized metrics to track performance and evaluate results [and]...establish standardized data collection requirements, with an emphasis on timeliness of reporting, for donor hospitals, OPOs, and transplant centers".¹

The study encourages collaboration between federal agencies to ensure relevant, accurate and timely data collection, collaboration with quality oversight organizations to develop standardized ways to evaluate and improve the organ transplant system, and modernized approaches to data collection for organ procurement and allocation. These are not requirements and were not created on behalf of the Health Resources and Services Administration (HRSA).

Summary of discussion:

A member asked whether other OPTN committees were reviewing the study; staff responded that committees were reviewing it ad hoc as it pertained to their focuses. The incoming Vice Chair commented that they felt a key focus overarching the study was the need for data collection efficiency.

A second member inquired if, relevant to the previous meeting's conversation on holistic data review, the Scientific Registry of Transplant Recipients' (SRTR) schedule for organ form review was available. The Chair responded that SRTR was only charged with reviewing the kidney forms as a non-contract task, and was not scheduled to do any other organs.

Next steps:

The Committee will review the NASEM report as a basis for creating DAC recommendations, and will consider possibilities for a standardized holistic data review process.

¹ National Research Council 2022. *Realizing the Promise of Equity in the Organ Transplantation System*. Washington, DC: The National Academies Press: S-15, accessed March 22, 2022. <https://doi.org/10.17226/26364>.

Upcoming Meetings

- April 13, 2022
- May 9, 2022
- June 13, 2022

Attendance

- **Committee Members**
 - Rachel Patzer
 - Sumit Mohan
 - Kristine Browning
 - Jamie Bucio
 - Heather Hickland
 - Lauren Kearns
 - Bilal Mahmood
 - Anna Mello
 - Daniel Stanton
 - Farhan Zafar
- **HRSA Representatives**
 - Adriana Martinez
- **SRTR Staff**
 - Bertram Kasiske
 - Ajay Israni
- **UNOS Staff**
 - Brooke Chenault
 - Colleen Flores
 - Cole Fox
 - Isaac Hager
 - Nadine Hoffman
 - Lindsay Larkin
 - Krissy Laurie
 - Elizabeth Miller
 - Tatenda Mupfudze
 - Samantha Noreen
 - Janis Rosenberg
 - Sharon Shepherd
 - Kayla Temple
 - Kim Uccellini
 - Trenece Wilson
- **Other Attendees**
 - Jesse Schold
 - Erika Lease