

OPTN Data Advisory Committee

Meeting Summary

June 3, 2021

Conference Call

Rachel Patzer, Ph.D., Chair

Sumit Mohan, M.D., M.P.H., Vice Chair

Introduction

The Data Advisory Committee (DAC) met via Citrix GoToMeeting teleconference on 6/3/2021 to discuss the following agenda items:

1. Policy Oversight Committee Update
2. Pre-Waitlisting Data Collection Project
3. Standardized Format for Pathology Report
4. Temporarily Inactive Code Revision and Expansion

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

1. Policy Oversight Committee Update

The Vice Chair and UNOS staff provided an update on the work of the Policy Oversight Committee (POC). POC is comprised of the Vice Chairs of the policy development committees and is charged with approving projects and ensuring the work is in alignment with broader OPTN goals. The POC also evaluates resourcing, sequencing, and sets priorities.

Summary of discussion:

The Vice Chair shared that the DAC has been involved in work on the strategic priority of efficient matching work by updating refusal codes and determining data to collect to define late turndowns.

UNOS staff commented that POC is currently reevaluating its role in assessing policy post-implementation. This includes developing a key metric during the approval process to determine a measurable goal of the project. The Chair commented that post implementation monitoring is important and asked how that evaluation information is brought back to the committees as well as disseminated more largely. UNOS staff commented that POC is considering ways to centralize this information.

A member of the public asked if the Biopsy workgroup is considering quality issues and variability when reading biopsy reports. The Vice Chair commented that in general, individuals are having issues with how procurement biopsies are read as well as how reliable the results are. The goal of the project is to increase standardization in processing and reporting to reduce variation and to also reconsider timing of completing biopsies.

A member asked how the POC reviews and incorporates public comments. UNOS staff commented that the sponsoring committees review comments and makes changes based on feedback, if necessary. The POC reviews proposals at various stages in the development process, including following public comment but before the Board of Directors reviews.

2. Pre-Waitlisting Data Collection Project

The Committee Chair provided an overview of a new project idea to collect pre-waitlisting data. Current OPTN data collection does not allow the evaluation of inequities in access to transplant for patients prior to listing for transplant. The proposed solution is to collect data on transplant candidates who are referred for and undergo transplant evaluation at OPTN member transplant programs. The data would include the date of referral and referring provider number as well as the date the transplant evaluation started and changes in status from the transplant referral form.

Summary of discussion:

The Chair shared that nearly 30 transplant programs nationally have submitted this data to Early Transplant Access Registry and the data elements being proposed are readily accessible in program's electronic medical records (EMR).

A member commented that this data is available in the Centers for Medicare and Medicaid Services (CMS) Quality Reporting System (EQRS) database. He commented that he would strongly support more data collection to allow better benchmarking with other programs to compare the length of time from patient referral to evaluation and evaluation to selection. This would assist in developing best practices. The Chair noted that referral information is not captured consistently and existing data in EQRS is limited to kidney.

The Vice Chair voiced his support for this project and noted the importance of having an accurate understanding of who is referred for transplant, who is evaluated, and who is being selected for transplant. A member commented that there should be reasons collected for why a patient is not evaluated.

A member commented that they support pursuing this project to an extent. She expressed interest in modifying an SRTR report that displays a program's waitlist distribution by race to also include expected values based on disease prevalence to allow comparison. She commented there may be other ways to get to the same goal faster. The Chair commented this approach would be easier to do for kidney since there is national surveillance data through the United States Renal Data System (USRDS) but there is not a data source for other organs. The Chair also noted that not all end stage renal disease (ESRD) patients are candidates for transplants.

A member suggested adding a data element to collect information on the dialysis unit as well as referring physician for kidney. The Chair commented that the dialysis unit would be listed on the referral form with the exception of pre-emptive kidney patients that are not receiving dialysis at a facility and may not have an associated CMS Certification Number (CCN).

A member raised a concern about developing definitions for referral and evaluation start date. He commented that having inconsistent definitions will lead to an inability to compare data across multiple programs. The Chair agreed and recommended basing the definitions on current standards and best practices. She noted that a working group would develop definitions and can share the definitions used for the Early Transplant Access Registry.

A member commented that if there are already best practices established, a faster approach could be creating guidelines. She commented that she frequently refers to the living donor follow-up best practice document.

A member raised a concern that this data collection would be a tremendous additional administrative burden on transplant programs. They commented that they are very hesitant to have additional data collection requirements, unless there is an expectation it would improve some provision of care. A

member commented that APIs should be developed to report the data to TIEDI. The Chair agree that APIs will be important to help ease any administrative burden and the project may focus on data elements that are readily available rather than those not already collected.

Next steps:

Member were invited to send additional feedback via email. The Chair will meet with collaborating committees to continue developing this project prior to POC review.

3. Standardized Format for Pathology Report

UNOS Kidney Committee staff provided an overview of this project which intends to reduce unnecessary biopsies and improve consistency and quality in biopsy performance. The proposed solution is a standardized biopsy report, for use by pathologists and transplant professionals during renal biopsy reading. This project also intends to expand current UNet™ biopsy entry field forms and improve reporting pathways for currently reported biopsy data.

Summary of discussion:

The Chair acknowledged that biopsies are performed at various time points and asked when this tool would be used. UNOS staff responded that the focus is on procurement biopsies. The Chair asked if this project could also be used for other organs such as liver. UNOS staff commented that the focus of the project is on kidney as biopsies are important to placement and allocation. UNOS staff commented that another workgroup may be formed to focus on the requirements specific to standardizing liver biopsies.

The Vice Chair asked if a renal pathologist is on the workgroup. UNOS staff confirmed this expertise is represented. The Vice Chair commented that there is a Banff consensus statement on procurement biopsies and recommended engaging this guideline's group. He also recommended including an end user of the data such as a surgeon and nephrologist. UNOS staff commented that there is broad representation on the workgroup including pathologist, OPO representatives, transplant surgeons, nephrologist.

The Committee endorsed this project.

4. Temporarily Inactive Code Revision and Expansion

A Transplant Coordinators Committee (TCC) member provided an overview of this project which intends to collect more granular data on temporary waitlist inactivation codes to help determine reasons that patients are unable to access transplant at a given time. The project will revise the temporary inactive codes with the primary focus on reducing the over use of code #7 "temporarily too sick" and code #3 "candidate work-up incomplete" by increasing the granularity of the options provided. The proposed data solution includes the following categories:

- Medical: Transplant-related
- Medical: Not transplant-related
- Candidate Access to Care
- Administrative
- Financial
- Emergency

Summary of discussion:

The Chair asked if users can select multiple options if the codes vary by organ type. The TCC representative commented that the user must pick the most relevant code and the same codes are used for all organs.

The Chair recommended making the “COVID-19 precaution” code to be more general in order to maintain relevancy in the future. The Vice Chair recommended referring to the updated list of refusal codes to identify ways to create consistency. The TCC representative commented that a member of the workgroup charged with updating the refusal codes is also participating on the workgroup revising the temporarily inactive codes. This member has provided helpful feedback including the recommendation to include a code for emergency considerations.

A member of the public asked if there has been any discussion regarding guidelines for when to make a patient inactive rather than internal hold. The TCC representative commented that the workgroup did not discuss this but would bring the recommendation back to the workgroup. The Vice Chair commented that good set of temporarily inactive codes could obviate the need for internal hold. He commented that patients might not even know they are on internal hold.

Committee endorsed this project.

Upcoming Meetings

- July 12, 2021
- August 9, 2021
- September 13, 2021

Attendance

- **Committee Members**
 - Rachel Patzer
 - Sumit Mohan
 - Alicia Redden
 - Benjamin Schleich
 - Bilal Mahmood
 - Colleen O'Donnell Flores
 - Daniel Stanton
 - Farhan Zafar
 - Heather Hickland
 - Kristine Browning
 - Macey Levan
 - Melissa McQueen
- **HRSA Representatives**
 - Adriana Martinez
 - Chris McLaughlin
- **SRTR Staff**
 - Bert Kasiske
 - Nick Salkowski
 - Michael Conboy
- **UNOS Staff**
 - Carly Engelberger
 - Courtney Jett
 - Kayla Temple
 - Kiana Stewart
 - Kimberly Uccellini
 - Kristine Althaus
 - Laura Schmitt
 - Leah Slife
 - Lindsay Larkin
 - Matt Prentice
 - Nicole Benjamin
 - Robert Hunter
 - Ross Walton
 - Sally Aungier
 - Samantha Noreen
 - Sarah Konigsburg
 - Savannah Holmes
 - Sharon Shepherd
- **Other Attendees**
 - Natalie Blackwell
 - Jamie Bucio