OPTN Data Advisory Committee
Pre-Waitlist Data Collection Workgroup
Meeting Summary
December 18, 2023
Conference Call

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

Introduction

The Data Advisory Committee Pre-Waitlist Data Collection Workgroup ("Workgroup") met via WebEx teleconference on 12/18/2023 to discuss the following agenda items:

1. Discuss Pre-Waitlist Data Dictionary

The following is a summary of the Workgroup discussions.

1. Discuss Pre-Waitlist Data Dictionary

The Workgroup discussed various goals for today's meeting based on the identified data elements and those being considered.

Summary of discussion:

Information was shared about the planned in-person meetings scheduled for January 9th and 10th in Richmond, VA. More information will be forthcoming to Workgroup members.

The Chair shared that in discussions with HRSA staff, it was asked whether the data proposed for collection could be submitted as part of a batch process, versus requiring information to be reported individually. HRSA and CMS will provide a response to the Workgroup in the future. The Chair said that HRSA staff confirmed that an important goal of the effort is to be able to link the collected pre-waitlist data with the existing registration data. Being able to document the patient journey is critical.

The Workgroup's discussion was categorized into the following goals:

- Goal 1: Affirm / review deliverable expectations
- Goal 2: Develop / confirm operational definition for referral
- Goal 3: Develop / confirm definition for evaluation
- Goal 4: Make progress on identifying data elements to include in referral and/or evaluation forms

The group discussed the goals of collecting pre-waitlist transplant data from patient referral through evaluation, selection committee, and waitlisting. The aim is to understand disparities and patient/center preferences in the system. There was debate around what constitutes a "referral" - whether it requires contact with a patient to proceed vs just an inquiry. Referrals may close for various reasons like inability to contact patients. The group proposed having standard reasons for closing referrals that centers could share.

Regarding data elements to collect, the group decided name, date of birth and gender would be required. Social Security Number (SSN) would be optional given legal/privacy hurdles for some centers pre-care. There was discussion around issues with collecting SSN at the time of referral. Two transplant

program representatives stated that they are barred from collecting SSN until the evaluation process starts. One of the representatives said that their program has stopped collecting it because of the potential for a data breach to expose patients to unnecessary risk.

Address and insurance status could provide other patient identifiers. Capturing all referrals, even for the same patient over time, was supported to count total referrals. The group considered allowing multiple referral dates to account for patients re-entering evaluation. Race and ethnicity data were noted as important but challenging to collect early and could remain optional.

The members were asked to identify the minimum amount of information required to generate the Medical Referrer Number (MRN). The members stated that the only information necessary are: first name, last name, date of birth, gender (sex assigned at birth). Workgroup members discussed the differences in functionality when comparing the electronic medical record (EMR) systems their programs use. Specifically, how the different EMR are organized to collect and report referral-related information.

There was discussion around patients referred but "too healthy" to proceed with evaluation. Some patients require re-referral later when sicker. The group debated capturing early incomplete referrals without enough data to proceed vs starting data collection once the patient is scheduled for evaluation. Overall, there was agreement on balancing data completeness with feasibility/burden on centers. The data would likely be submitted in batches rather than real-time. There is still refinement needed on definitions and timepoints for data capture.

Next steps:

The Workgroup will work toward preparing for the in-person meeting in January and will build out data elements in the workbook.

Upcoming Meeting

- January 9, 2024 – In-person meeting
- January 10, 2024 – In-person meeting

Attendance

- **Workgroup Members**
  - Sumit Mohan
  - Marie Budev
  - Kate Giles
  - Christine Maxmeister
  - Hellen Oduor
  - Jennifer Peattie
  - Julie Prigoff
  - Martha Tankersley
  - Megan Urbanski
- **HRSA Representatives**
  - Vanessa Arriola
  - Adriana Martinez
  - Chris McLaughlin
- **SRTR Staff**
  - Ryo Hirose
  - Jon Snyder
- **UNOS Staff**
  - Cole Fox
  - Darby Harris
  - Gabrielle Hibbert
  - Nadine Hoffman
  - Sevgin Hunt
  - Beth Kalman
  - Kieran McMahon
  - Lauren Mooney
  - Laura Schmitt
  - Kayla Temple
  - Divya Yalgoori
  - Anne Zehner
- **Other**
  - Rachel Patzer