OPTN ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK

OPTN Data Advisory Committee
Pre-Waitlist Data Collection Workgroup
Meeting Summary
January 16, 2024
Conference Call

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

Introduction

The Pre-Waitlist Data Collection Workgroup met via Webex teleconference on 01/16/2024 to discuss the following agenda items:

1. Finalize artifacts for referral, evaluation, and selection committee data collection
2. Discuss monitoring methodology

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

1. Finalize artifacts for referral, evaluation, and selection committee data collection

The Workgroup members reviewed and commented on the workflows, data elements, and in some cases, data definitions associated with the proposed data collection around the referral, evaluation, and selection committee stages prior to waiting list registration or not being registered on the waiting list.

Summary of discussion:

The Workgroup members had been provided with the meeting slides and access to the pre-waitlist data collection workbook. The workbook consists of tabs in which are identified the different stages of the pre-waitlist registration process. The stages consist of referral, evaluation, and selection committee. The workbook tabs identify the data elements the Workgroup has indicated are associated with each of the stages. In addition, the workbook contains workflows created to reflect the steps and decisions points within each stage.

The stated goal of the Workgroup meeting was to finalize the data elements for collection and to come to consensus around certain business rules associated with the pre-waitlist registration stages.

The Workgroup agreed with the previous decision to require quarterly reporting of all patient referrals and self-referrals for transplant services. Transplant programs will not be asked to backfill data for current patients, as part of the proposed collection effort. Collection and reporting would begin with new referrals.

It was agreed that each of the stages would be identified using one of the three following categories: active, closed, or canceled. Canceled was included as a way of managing reporting errors, as a way to allow the transplant program to cancel a submission if they submitted the data by mistake, for example, or if the data was mapped incorrectly on a transplant program's electronic medical record (EMR). The Workgroup members also discussed, and ultimately rejected the idea, that the OPTN should 'administratively cancel' a referral or evaluation record that indicated no updates or changes over three consecutive years. Members indicated it would be more appropriate for the OPTN to notify programs directly when such events are identified, but in the end, it should remain a program's decision whether or not to 'cancel' a patient's record due to inactivity. A member states that providing such feedback to

the transplant program and letting the program determine the reasons involved and whether or not to remove the candidate is a better way to approach the issue. Additionally, the member commented, that over several cycles, the quality of the data should improve as the programs become more knowledgeable about the feedback loop. Workgroup members also confirmed that as part of the required quarterly data updates, transplant programs would have to confirm that their patients are or are not in the same status that the patient was in at the time of the previous update. As a result, this proposed confirmation also alleviates the need to include an auto-cancellation activity. It was mentioned that there have been discussions about creating reporting within the OPTN Computer System to assist transplant programs monitor the status of patients who are in the pre-waitlist stages for an extended period of time.

The Workgroup next took up discussions of the deliverables that are due to HRSA by January 31, 2024. OPTN Contractor staff displayed that workflows diagrams that were created for the referral, evaluation, and selection committee stages of the pre-waitlist registration process. OPTN Contractor staff also talked through each workflow to ensure Workgroup members were in agreement. The flow charts were based on previous Workgroup discussions of the referral start, the evaluation start, the patient moving forward to the selection committee stage, and from selection committee to waitlist registration or not. The members agreed with the steps identified. The Workgroup members reviewed the definitions of the start and end trigger events identified for the referral, evaluation, and selection committee events. Based on the Workgroup members' feedback, the definitions were revised to provide programs with greater clarity about the intent of the events.

The Data Advisory Committee Chair explained that, at least initially, a bulk upload approach would be used when collecting transplant program data. The process was described as similar to having a flat file for uploading where each of the columns could be a discrete field in a single form.

The new data elements identified for collection were shared with the Workgroup members, and feedback was requested. In addition to the proposed elements, there was also discussion about whether the Workgroup should specify which type of phone number should be collected? For example should it be made clear that a cell phone number should be provided or a home number? The reason for the question was that the type of phone number might be beneficial when it comes to linking the pre-waitlist information with the waitlist registration information already collected by the OPTN.

<u>Next steps:</u>

The Workgroup members were reminded of the January 31, 2024 deadline to provide information to HRSA staff. The members were asked to review the proposed data elements and workflows with as much attention to detail as possible. If they did identify any issues, they were asked to notify OPTN Contractor staff as soon as possible in order for the workbook to be revised. The information discussed during the meeting will be provided to the OPTN Data Advisory Committee (DAC) for review and endorsement as part of DAC's January 22, 2024 meeting.

2. Discuss monitoring methodology

The Workgroup did not discuss the monitoring methodology due the comprehensiveness of their discussion of the referral, evaluation, and selection committee data collection.

Upcoming Meeting

- DAC Committee meeting – January 22, 2024

Attendance

- **Workgroup Members**
  - Sumit Mohan
  - Jesse Schold
  - Leigh Ann Burgess
  - Ashley Cardenas
  - Gaurav Gupta
  - Adrian Lawrence
  - Krista Lentine
  - Christine Maxmeister
  - Karl Neumann
  - Hellen Oduor
  - Jennifer Peattie
  - Julie Prigoff
  - Reem Raafat
  - Martha Tankersley
  - Megan Urbanski
- **HRSA Representatives**
  - Adriana Alvarez
- **SRTR Staff**
  - Ryo Hirose
  - Ajay Israni
  - Jon Snyder
- **UNOS Staff**
  - Brooke Chenault
  - Jonathan Chiep
  - Bonnie Felice
  - Darby Harris
  - Sevgin Hunt
  - Beth Kalman
  - Eric Messick
  - Lauren Mooney
  - Laura Schmitt
  - Divya Yalgoori
  - Anne Zehner
- **Other Attendees**
  - Rachel Patzer