OPTN ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK Meeting Summary

OPTN Data Advisory Committee
Pre-Waitlist Data Collection Workgroup
Meeting Summary
December 13, 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 12/13/2023 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 data elements for potential inclusion into the pre-waitlist data dictionary, triggering events, and preventing data burden.

Summary of discussion:

The Chair stated that it is important for the Workgroup members to remember that the goals of proposing this data collection are to identify issues around the accessibility of transplantation and to identify the differences across programs in terms of the thresholds used to determine whether a patient is evaluated and/or selected for waitlist registration. The Chair also made it clear that collecting the data for research purposes is not a goal of this effort. A member opened the discussion by describing the potentiality of data that may change over the course of a patient's journey prior to waitlist registration (also described as data leakage). The Workgroup should be considering ways to track the population of patients who never get to the next step. The member noted that insurance is an example of data that can change over time. The member said that the Workgroup could work to capture insurance data at each point in the patient journey because insurance can change over time. The Chair suggested duplicating data capture efforts as a potential solution to halt data leakage.

The conversation then changed to discuss the definition of a referral. Several members shared their ideas about a referral definition, based partially on how their transplant programs use the term. It was noted that there may be a large variation between what is defined as a referral and the types of information captured at referral. There was also discussion of referrals from the perspective of how much information or what kinds of information should be required in order to consider something a "full referral" or maybe a "partial referral?" If that is a consideration moving forward, which might be more useful? A member responded with the idea that this could give the Workgroup an opportunity to standardize a referral form. A Workgroup member noted that there are a variety of avenues for referrals that can impede the standardization process, noting that the creation of a standardized form could be challenging. Another member indicated that their program collects most information at the time of evaluation, and very little information at the time of referral. As a result, some of what is being discussed would be a heavy lift for similarly-situated programs. This has the potential to significantly expand the data burden programs experience. However, the Chair noted that this is a challenge that could help the Workgroup figure out the minimum required information. The Vice Chair also noted that this could give the Workgroup the opportunity to build their own definition of referral.

A Workgroup member noted that adding a pre-waitlist form could create more data burden. The Workgroup then transitioned to discussing what defines a triggering event for pre-waitlist data collection. One member noted that a trigger event occurs when a transplantation center receives a fax or phone call. Another Workgroup member mentioned that they define a trigger event as the time at which a consent form is filled out. Other members noted that the Workgroup would need to define what would constitute as a triggering event that could apply to all transplantation centers. After, the Workgroup discussed the basic demographic information that would need to be added at the point of referral. A member of the Workgroup asked whether the goal of the pre-waitlist data collection Workgroup is to capture the total number of patients considered for transplantation or whether the goal of the Workgroup is to capture the most data related to transplantation. Members of the Workgroup then discussed the referral and evaluation “start” and “stop” criteria to include, noting the importance of capturing data potentially relevant to “start” and “stop” criteria.

As part of this effort, the capacity exists to not be as rigorous around the timeframe of collecting pre-waitlist data. The data elements being considered are not time sensitive like the data is in the OPTN’s Computer System for candidates registered on the waiting list. The Chair noted that to help ease data burden, the Workgroup could utilize batch referrals in a batch report form. This would ease the data burden because processing real time data would be time and resource prohibitive for transplantation centers. In addition, the Chair noted that the Workgroup could strive to inform transplant centers early. The Vice Chair then noted that the Workgroup could include a survey for these forms to ensure that there is community input.

There was discussion regarding what constitutes the most basic set of data elements that is necessary? Members discussed elements such as that enough information is available for a transplant program to contact the patient: patient name, date of birth, gender, referring provider, phone number, date of referral, address, and zip code. A member described the process used by their program to validate patient information, including validating against other data sets. Their program also focuses on obtaining basic demographic information about a patient, the referring provider, and the dates of the relevant data that are being sought. They do not collect clinical information or information about the patient’s background. Another consideration for the Workgroup is how this information is collected within their existing electronic medical record systems and the changes to those systems that might be necessary to capture the data elements being discussed. There is data burden associated with that as well. The Workgroup should put as a parking lot item working with the EMR vendors to address these data elements / process steps in their future builds.

The Vice Chair raised the subject of creating a structured feedback opportunity for transplant programs about their activities. The feedback could provide comparisons of a program’s population to the national population, what a program’s timelines are for referral through selection compared to all programs. Basically, identifying the information / tools that would be useful for a transplant program to assist with internal discussions, benchmarking, and/ or quality initiatives. Other Workgroup members agreed that it is a good idea and could help offset issues arising from the extra data burden associated with the increased collection. A member pointed out that this might give programs an opportunity to access progression times and volumes at local, regional, and national levels and that is information that programs have not had access to previously. It was pointed out that the initial thought is that this would not be public available data, but instead available to the programs for self-review.

At the end of the discussion, the Chair noted that the next session the Workgroup will need to look at lessons learned, gain consensus on the definition of a referral, and figure out what types of data elements at the referral level can be operationalized at the national level.

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

- December 18, 2023

Attendance

- **Workgroup Members**
    - Sumit Mohan
    - Jesse Schold
    - Kate Giles
    - Christine Maxmeister
    - Jennifer Peattie
    - Julie Prigoff
- **HRSA Representatives**
- **SRTR Staff**
    - Jon Snyder
- **UNOS Staff**
    - Cole Fox
    - Gabrielle Hibbert
    - Nadine Hoffman
    - Sevgin Hunt
    - Beth Kalman
    - Eric Messick
    - Sharon Shepherd
    - Laura Schmitt
    - Kim Uccellini
    - Divya Yalgoori
    - Anne Zehner
- **Other**
    - Rachel Patzer