

**OPTN Data Advisory Committee
Pre-Waitlist Workgroup
Meeting Summary
December 1, 2023
Conference Call**

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

Introduction

The Data Advisory Committee Pre-Waitlist Workgroup (“Workgroup”) met via WebEx teleconference on 12/01/2023 to discuss the following agenda items:

1. Review Health Resources and Services Administration (HRSA) Request & Review DAC Deliverables and Timelines
2. Pre-Waitlist Workgroup

The following is a summary of the workgroup discussions.

1. Review Health Resources and Services Administration (HRSA) Request & Review DAC Deliverables and Timelines

The workgroup reviewed the HRSA request for the DAC and Membership and Professional Standards Committee (MPSC) to draft referral an evaluation registration data collection and ventilated referral notification data for feedback by January 31, 2024. The workgroup also reviewed the timeline for the workgroup.

Summary of discussion:

There was no discussion.

Next steps:

The workgroup will meet for an in-person workgroup session in the beginning of January.

2. Pre-Waitlist Group

Support staff for the workgroup review the timeline and align on group logistics.

Summary of discussion:

The Chair noted that the workgroup should strive for an agnostic data collection system. The Chair additionally called for providing subject matter experts for the workgroup, with the Vice Chair echoing the comments of the Chair. An SRTR staff member noted that instead of starting from scratch, there are opportunities to analyze data elements that already exist and further noted that the data definitions that are chosen should be clear and succinct. The Chair added to the discussion by noting that the workgroup should pay attention to analyzing a trigger event that leads to the collection of data elements. A HRSA representative noted that the baseline for defining data elements can be flexible, due to the need to remain cognizant of data burden.

Another support staff to the workgroup discussed that the approach for the workgroup should consist of three parts: analysis, design, and recommendation. The workgroup then discussed adding various

stakeholders such as transplant coordinators to the workgroup, with other workgroup members mentioning that some of the participants do have that background. The workgroup also placed an emphasis on building what is best for the community and what is reasonable to do in the allotted timeframe. A workgroup member made note of possibly building a large database of already available data elements and systematically culling elements that are not needed.

Next steps:

Support staff to the workgroup provided a workbook that the workgroup members can add data elements to. The workgroup will also figure out other subject matter experts to bring to the workgroup. Both the Chair and Vice Chair will create a 'strawman' focused on the minimum amount of data elements to include to help kick off discussion during the in person meeting in early January.

Upcoming Meeting

- December 13, 2023

Attendance

- **Workgroup Members**
 - Sumit Mohan
 - Jesse Schold
 - Christine Maxmeister
 - Hellen Oduor
 - Julie Prigoff
- **HRSA Representatives**
 - Adriana Martinez
 - Chris McLaughlin
- **SRTR Staff**
 - Ryu Hirose
 - Jon Snyder
- **UNOS Staff**
 - Brooke Chenault
 - Jonathan Chiep
 - Darby Harris
 - Gabrielle Hibbert
 - Nadine Hoffman
 - Houlder Hudgins
 - Sevgin Hunt
 - Beth Kalman
 - Eric Messick
 - Lauren Mooney
 - Samantha Noreen
 - Sharon Shepherd
 - Laura Schmitt
 - Divya Yalgoori
 - Anne Zehner
- **Other Attendees**
 - Jacqueline Rodriguez