OPTN Data Advisory Committee
Meeting Summary
October 26, 2020 3:00 PM EST
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 10/26/2020 to discuss the following agenda items:

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

1. Policy Oversight Committee (POC) Update
2. Data Submission Tools Demonstration
3. Organ Procurement Organization (OPO) Committee Update on the Deceased Donor Registration (DDR) Form
4. Data Collection to Assess Socioeconomic Status & Access to Transplantation

1. Policy Oversight Committee (POC) Update

The Vice Chair updated the Committee on the Policy Oversight Committee's (POC) strategic policy priorities, project alignment, and project sequencing.

Summary of discussion:

A member asked, based on much of the POC work categorized as "other", if there needed to be more focus towards strategic policy priorities. The Chair responded that the strategic policy priorities are new, so the work categorized as "other" makes up those projects which did not fit into the new priorities at that time of development.

While not related to data collection, a member suggested the POC review policy related to preservation from a transplant center perspective. Staff suggested to bring this idea to Operations and Safety Committee leadership for further discussion.

There were no additional questions or comments.

2. Data Submission Tools Demonstration

UNOS staff from the Research Department demonstrated the tools developed based on the DAC proposal, *Modify Data Submission Policies*.

Summary of discussion:

The Data Lock Preview Report provides OPTN members with a way to review and correct data submitted on impacted forms prior to the forms being "locked". The Data Lock Dashboard provides OPTN members with a dashboard to compare the quality of their data, monitor changes, and review the frequency and reasons for "unlocking" forms.

A member asked if the Data Lock Preview Report has the ability to be filtered. UNOS staff responded that the Reports are organ specific, as well as separated by recipient and living donor data. Additionally, the Reports are Excel spreadsheets which allow for further filtering abilities.

Members agreed the tools were a great development.

There were no additional comments or questions.

3. Organ Procurement Organization (OPO) Committee Update on the Deceased Donor Registration (DDR) Form

The Chair of the OPO DDR Review Workgroup presented the DAC with an update on the status of the project. The Workgroup's recommendations will go out for public comment in Winter 2021.

Summary of discussion:

The OPO DDR Review Workgroup is the first attempt to review existing data. The Workgroup seeks to improve the consistency of the DDR for OPO staff. The Workgroup utilized the Data Element Standard of Review Checklist while reviewing the DDR. The Workgroup has reviewed approximately 200 data elements. Currently, no additional data elements are being proposed. There are 4 deletions and 25-30 modifications.

The Chair asked about the representation of the Workgroup. Staff responded that there are OPO representatives as well as DAC representatives.

The Chair asked how this work addresses other forms where there is overlap between data elements. Staff responded that the Workgroup has not reviewed other forms, but as the process continues the DAC could refer to the updates the Workgroup contributed to the Help Documentation. Staff explained that the Workgroup has considered the consistency across some data collection efforts, such as information on DDR which comes from the Death Notification Registration (DNR).

A member asked where the pumping parameters will be placed. Staff responded that perfusion and pumping data collection, across organs and across forms, is being discussed by the Broader Distribution Data Collection Workgroup. Another member responded that there are some pumping data collection on the DDR. The Chair emphasized that perfusion and pumping data collection conversations should include DAC representation.

There were no additional comments or questions.

4. Data Collection to Assess Socioeconomic Status & Access to Transplant

The Minority Affairs Committee (MAC) presented their proposal, *Data Collection to Assess Socioeconomic Status (SES) and Access to Transplant*, and requested feedback from the DAC.

Summary of discussion:

The Chair stated their support of collecting income data within the suggested brackets. The Chair explained the importance of collecting income data to better understand disparities and added that brackets allow for the data to be collected in a less intrusive way while still being valuable. Additionally, the Chair expressed support for education to the community of how the information from SES data collection will be used. The Chair agreed that an "information not available" option should be added.

A member expressed concern regarding "total assets". The member explained whether intended or not it might be taken as a precursor to care. Members agreed that this data element would not gain trust with the patient population.

The Chair suggested the MAC should research what data programs already collect. UNOS staff responded that some programs do collect financial data but it varies in the way it is collected. The Chair stated that SES information should be collected at time of waitlisting and time of transplant.

A member suggested collecting data related to whether candidates are on Medicaid or Medicare. The member stated that collecting data on other public assistance programs, such as Supplemental Nutrition Assistance Program (SNAP), is not necessary. The member suggested discussing the purpose of collecting data regarding participation in public assistance programs and if there was an ability to make generalizations. Additionally, the member asked if there is data collected on literacy levels. The Chair responded that literacy data is not collected.

The member suggested analyzing zip codes and available health resources in the areas. UNOS staff responded that the MAC is proposing collecting individual level data to be able to understand the problem, and that zip code and county level data are not sufficient.

Another member asked if the household income brackets are similar to census level data brackets in order to compare data. UNOS staff explained that the brackets increase in 10,000 increments, which the MAC thought would make patients comfortable as well as allow information to be gained. The Chair suggested the MAC should verify the best practices regarding bracketing data collection measures.

Overall, the DAC supports this proposal.

Additionally, a member suggested working with the MAC to separate race/ethnicity fields into two distinct fields.

Upcoming Meetings
- November 9, 2020 (teleconference)
- December 14, 2020 (teleconference)

Attendance

- **Committee Members**
    - Alicia Redden
    - Benjamin Schleich
    - Bilal Mahmood
    - Colleen O'Donnell Flores
    - Daniel Stanton
    - Farhan Zafar
    - Heather Hickland
    - Kristine Browning
    - Lauren Kearns
    - Macey Henderson
    - Melissa McQueen
    - Rachel Patzer
    - Sandy Feng
    - Sumit Mohan
- **HRSA Representatives**
    - Adriana Martinez
- **SRTR Staff**
    - Jon Snyder
- **UNOS Staff**
    - Adel Husayni
    - Anne Zehner
    - Brooke Chenault
    - Kelley Poff
    - Kim Combs
    - Lauren Mauk
    - Matthew Prentice
    - Meghan McDermott
    - Pete Sokol
    - Randall Fenderson
    - Rebecca Murdock
    - Robert Hunter
    - Ross Walton
    - Sarah Taranto
- **Other Attendees**
    - Jeffrey Trageser