**OPTN Data Advisory Committee
Holistic Data Review Workgroup
Meeting Summary
September 23rd, 2022
Conference Call**

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Introduction

The Holistic Data Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 09/23/2022 to discuss the following agenda items:

1. Administrative Items
2. Follow-Up on the Initial Meeting Discussion

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

1. Administrative Items

The Workgroup discussed various administrative items for Workgroup feedback and consideration.

Summary of discussion:

UNOS Enterprise Data Management Staff identified upcoming meeting dates with conflicts, specifically Veterans Days, the day after Thanksgiving, and the day before Christmas Eve. The workgroup identified alternative dates to reschedule those meetings.

The Workgroup discussed whether 'data subject areas' or 'data domains' is a more appropriate term to use when broadly categorizing OPTN data. The target audience who will be using the categories includes the OPTN Board of Directors and the Committees, which represent a broad audience with varying levels of data familiarity. The Workgroup agreed that data-friendly terminology would be preferable for their audience and opted to use 'data subject areas.'

Members were asked if they had any feedback on the general approach of the Workgroup or process for dividing work. Members did not have feedback at this time but were encouraged to maintain an open dialogue and provide feedback as meetings progress.

Next steps:

The committee support staff will send out updated meeting invites to reflect the Workgroup's decision.

2. Follow-Up on the Initial Meeting Discussion

Staff highlighted the workbook's updates since the last meeting on 09/09/2023 and discussed items in the parking lot section of the workbook.

Summary of discussion:

The Workgroup discussed how collaboration with other OPTN Committees on various data elements would occur as the data review proceeds. Members suggested that in some scenarios an organ-specific committee would be responsible for data elements that are unique to them, while the DAC could oversee data elements that are used across multiple organ types. It was also mentioned that a process is

needed to ensure that the importance of continued work on data quality is addressed in light of the turnover of OPTN Committee members. The group discussed the differences between optional, required, and critical data. It was discussed that while no official definition exists, for these purposes, critical data were identified as data that is required to collect and critical to what is occurring (i.e. could not be listed or accept any organ offer without this data). Furthermore, data accuracy and quality are critical to ensuring the process operates effectively and efficiently.

The Workgroup reviewed the questions in the parking lot worksheet. The first question inquires about the follow-up process and specimen storage for living donors whose procurement occurs at a different center than the transplantation in scenarios like kidney-paired donation (KPD). The group agreed that the Living Donor Committee would be the primary committee responsible for the data element, with the Patient Affairs Committee (PAC) serving as a potential stakeholder.

The second question asked which data subject area functional status would best align. The functional status question reflects the patient's ability to perform various tasks independently or with a varied level of assistance. The group felt that the data element did not fit the existing subject areas in the workbook and needed an additional one. Members considered what other data this item would connect to and identified 'working for income' as a similar type of information. After consideration, the group elected to develop a new category titled 'Patient Assessment Data' for these data elements. Members noted that this data, along with much of the other social data, is patient-reported.

Next steps:

Members are asked to review the workbook saved to SharePoint, specifically the parking lot section, and answer any questions they can or add questions they want to be answered. Members are asked to add their initials next to their questions and answers to discuss further if needed.

Upcoming Meeting
- October 14, 2022
- October 28, 2022

Attendance

- **Committee Members**
    - Colleen O'Donnell Flores
    - Kirshnaraj Mahendraraj
    - Rebecca Baranoff
- **HRSA Representative**
    - Adriana Martinez
    - Adrienne Goodrich-Doctor
- **SRTR Staff**
    - Ajay Israni
    - Bert Kasiske
    - Jon Synder
- **UNOS Staff**
    - Brooke Chenault
    - Isaac Hager
    - Eric Messick
    - Janis Rosenberg
    - Kimberly Uccellini
    - Krissy Laurie
    - Laura Schmitt
    - Nadine Hoffman
- **Other**
    - Christine Maxmeister