**OPTN Data Advisory Committee**
**Holistic Data Review Workgroup**
**Meeting Summary**
**September 9th, 2022**
**Conference Call**

**Jesse Schold, PhD, M.Stat., M.Ed., Chair**

**Introduction**

The Holistic Data Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 09/9/2022 to discuss the following agenda items:

1. Administrative Items
2. Follow-Up on the Initial Meeting Discussion
3. Approaches to Holistic Data Review

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

**1. Administrative Items**

Enterprise Data Management Staff reported out on the timeline established at the previous meeting as well as the content for the report.

Summary of discussion:

A member asked what an example of a source of external data that could be used by the OPTN was. Staff replied that a social determinants of health database would be an example, as it's not data gathered by the OPTN but could be used by the OPTN. A SRTR representative also suggested pharmacy claims data as a possibility to make inferences about a recipient's health post-transplant.

A member also expressed interest in reviewing the OPTN forms in aggregate, and requested they be made available in one place. Staff replied that they would share an aggregate file with the member.

Next steps:

Staff will provide an aggregate file of transplant forms to be reviewed en masse.

**2. Follow-Up on the Initial Meeting Discussion**

Staff continued a discussion on the projects currently in flight by Enterprise Data Management.

Data summary:

Code standardization project:

- Improve interoperability of OPTN codes
  - Ease burden of data exchange
- Improve data quality
- Improve data consistency

Progress to date of code standardization:

- Create and disseminate request for proposals

- Engage subject matter experts
- Compile list of recommendations

Summary of discovery phase:

- OPTN data elements largely do not conform to an existing standard, cannot be linked in current form
- TIEDI Data collection aligned broadly with 8 clinical data categories
- Recommendations:
    - Identify most granular data elements
    - Align most broadly used data elements first (consider which are used by EHRs)
    - Catalogue OPTN data elements that are not standardized

Summary of discussion:

In discussing the code standardization project, a member wondered whether there were any industry standards used in developing OPTN code sets. Staff replied that most, if not all, were developed independently by the OPTN. The member also asked if there were any plan to shift to industry standard codes; staff replied the only alignment currently planned is for data definitions.

The Chair supported the approach, timeline, and current progress done by staff, but suggested including more intermediary milestones to ensure that there are distinct check-in points, especially for organ-specific committees. Staff expressed concern that too many check-in points could delay the overall progress of the project, as the largest benefit of it comes after its completion. They also worried about the project becoming too broad in scope with too much input. The Chair agreed, and added that a key goal for the project must be standardizing data elements in a way that is strategic about the areas of greatest need first. Furthermore, it was suggested that, in building this review process, consideration needs to be given to future policy development, and building a system that is nimble enough to quickly address change.

Next steps:

Staff will consider the Workgroup's feedback.

3. **Approaches to Holistic Data Review**

Staff presented on the possible approaches for holistic data approaches, and requested committee feedback on which was optimal.

Data summary:

Methodology:

- Drafted OPTN data subject areas and attempted align with OPTN Committees
- Feedback requested on:
    - The accuracy of the alignment
    - What to do with the left over data elements
    - What data quality concerns are known already about specific elements
- Data elements were also categorized by subcategory
    - Event – triggered by an event occurring
    - Transactional – gathered and reported every time
    - Vertical – organ-specific data
    - Horizontal – data gathered across organ groups

Summary of discussion:

Staff inquired whether specific data elements collected at different times (e.g. a living donor who later becomes a deceased donor) should be joined together in some fashion. In this case, there is certain "master" data that is very unlikely to change with time: social security number, date of birth, blood type, etc.. In addition, staff also questioned whether candidate data should be isolated from recipient data, as certain types of data are gathered in two separate data elements, but should remain the same from candidacy to post-transplant reporting.

The Chair supported gathering the data at each "status change", given that different data elements will already be gathered because of the different data collection needs of that status.

It was suggested that in the alignment project, there could also be notes taken on where gaps in data collection are. Staff replied that adding new data elements may not be in scope of the alignment project, but agreed that knowing where gaps exist is very useful information to inform the committee which oversees the data elements.

The Chair hypothesized that some data elements may change from vertical to horizontal over time, and those elements should be designed such that they can be shifted from vertical to horizontal as more organ groups use them. They emphasized that performing prospective analyses of data elements would help ensure the overall success of the review process.

Next steps:

Staff requested members review the data elements document and add to/edit as needed, include commentary on data elements with quality concerns, and identify areas that need further discussion.

**Upcoming Meeting**

- October 14, 2022

**Attendance**

- **Committee Members**
  - Jesse Schold
  - Colleen O'Donnell Flores
  - Kirshnaraj Mahendraraj
- **SRTR Staff**
  - Bert Kasiske
- **UNOS Staff**
  - Brooke Chenault
  - Isaac Hager
  - Nadine Hoffman
  - Eric Messick
  - Janis Rosenberg
  - Kimberly Uccellini
  - Laura Schmitt
  - Anne Zehner