

**OPTN Data Advisory Committee  
Holistic Data Review Workgroup  
Meeting Summary  
February 24, 2023  
Conference Call**

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

## **Introduction**

The Holistic Data Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 02/24/2023 to discuss the following agenda items:

1. Discuss Workgroup Meeting Frequency
2. Homework Discussion
3. Data Analysis Exercise (Primary Diagnosis)
4. Review Updates to OPTN Data Subject Areas
5. Homework Discussion

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

### **1. Discuss Workgroup Meeting Frequency**

The Workgroup reviewed the upcoming Workgroup meeting dates, as follows:

- February 24, 2023, 1 to 2:00 pm (ET)
- March 24, 2023, 1:00 to 2:00 pm (ET)
- April 28, 2023, 1:00 to 2:30 pm (ET)
- May 22, 2023, 1:00 to 2:30 pm (ET)
- June 23, 2023, 1:00 to 2:30 pm (ET)

### **2. Homework Discussion**

The Workgroup was asked to consider the following questions:

- What are the benefits of using ICD-10/standard healthcare terms?
- How can we leverage ICD-10 codes/standard healthcare terms to measure pre- and post-transplant outcomes?

#### Summary of discussion:

A member noted that their transplant program does not utilize ICD-10 to monitor transplant outcomes. The member added that their transplant program does have frequent discussions regarding whether ICD-10 is an appropriate way to capture patient clinical status. The member stated that Vizient has a metric which focuses on survivability of transplant patients that are admitted or readmitted to the hospital. The member stated that Vizient utilizes ICD-10 codes and it has been noted in their transplant program that the coding might not be reflect of actual patient clinical status or risk factors, especially when transplant providers are not the ones listing the codes. The member stated they would have concerns regarding interfacing with electronic medical records (EMRs) to pull data.

Another member agreed. The member stated their transplant program does not utilize ICD-10 for post-operative complications or related information. The member stated that primary diagnosis seems to be

a standard approach. The member stated their transplant program utilizes registering reporting in the EMR for import and export perform data. The member explained that anything diagnostic related requires additional validation in their transplant program. The member stated that use of ICD-10 may be a beneficial goal, however there is currently not a practical use for it.

A member noted that ICD-10 sometimes requires multiple codes to account for the whole diagnosis. The member stated that a challenge with ICD-10 is that EMRs do not collect information in the same way. The member stated overcoming this challenge is a critical part of developing a solution. The member stated that challenges with documentation and entering accurate diagnosis codes remains an issue no matter which code is utilized.

Another member stated that Vizient utilizes ICD-10 codes on the time of admission. The member noted this is an issue because diagnosis at the time of admission may not be an accurate depiction of an individual's health status.

### **3. Data Analysis Exercise**

The Workgroup performed a data analysis exercise.

#### Summary of discussion:

A member noted that transplant program staff is very aware of what a primary diagnosis needs to be at time of list as well as at the time of transplant because the risk ratio is dependent on it. The member stated that primary diagnosis is in their transplant module within the EMR because it is not changeable to anyone except those who have security access to that section of the chart. The member stated that the primary diagnosis is then entered manually or via import/export features. The member stated that they could see how ICD-10 could be mapped to this. Another member stated their transplant program functions the same with in regards to primary diagnosis data. The member noted that the options for primary diagnosis align with the OPTN data collection primary diagnosis. The member explained that the Phoenix module aligns with OPTN data collection.

A member stated that the description for primary diagnosis should be understandable for anyone with medical knowledge. Another member agreed. The member added that it is required to document the indication for transplant, which the majority of the time is the primary diagnosis.

A member asked if a patient is re-transplanted whether their primary diagnosis should be the original medical reason for organ failure or graft failure. Another member stated that a re-transplant would be the reason for a re-transplant, but there is the opportunity to add additional information.

A member noted that disease occurrence is a more nebulous data field. The member stated that this is in the notes as well as a drop-down for that the providers input the answer. The member stated that it is not a discrete field.

Another member stated that discrete fields are great for data abstraction, however documenting in the body of notes is not able to be utilized via data abstraction. The member explained that data documented within notes require manual chart review and data input.

### **4. Homework Discussion**

The Workgroup was asked to consider the following questions:

- Trace the diagnosis data in your local clinical information system
  - Data definition, data type, design?
- What are the data collection steps for reporting?
- Volunteers? When/where do you document social determinants of health data?

- Follow-up question? Draft OPTN Data Subject Areas workbook

Summary of discussion:

The OPTN data specifications are shared with the community, and there are local mappings and builds that are performed to satisfy the requirement. The Workgroup members were asked to identify any challenges they could foresee if ICD-10 codes are added to the requirements, given the existing circumstances. Members were asked to think about how the information is used and stored in their local systems, as well as what are the constraints associated with it and what recommendations might there be to ensure the appropriate patient information is being captured? For example, what does it mean to members if manual data extraction has to be performed, or what does it mean to a program's reporting timelines? Staff also indicated that they are interested in any volunteers to provide information about their program's use of Social Determinants of Health data. Of special interest are opportunities to add program's requirements into the IT roadmap. What are members thoughts about incorporating ICD-10 codes into their OPTN data reporting activities.

One Workgroup member indicated it would be feasible to share those questions with their IT support teams. Another member stated that the questions had already been submitted to the medical and surgical directors. The member also indicated support for potentially including the SDoH data elements in what is being reported, because in some cases the information is already reported. There certainly would be an associated administrative burden of reporting, but having the information in the OPTN system would be very beneficial.

Staff mentioned that a data standardization effort will be starting soon, and this is an opportunity to get ahead of that effort. A Workgroup member asked whether inviting some of the large electronic medical record vendors has been considered as part of this effort, because those groups might be able to have a larger impact on adoption. Staff stated that the vendors will definitely be part of the discussion around a solution. The Workgroup will be kept in the loop about the impact of the standardization effort holistically on the transplant community. That will be part of the plan that is shared with the Board, so that information will be brought before the Workgroup for consideration of ways that all sides can work together.

It was mentioned that the standardization effort could result in additional benefits that weren't previously considered. However, a member pushed back on the concept that utilizing ICD-10 codes would create a new standard because the process for arriving at what diagnosis code and therefore, what ICD-10 code to use is not going to change. The effort being described is standardizing the way data are collected and reported. It is unlikely that the effort will change or improve transplant center practices or performance. Ultimately, the information provided to the OPTN should be the same information provided to CMS and the commercial insurers. Staff agreed with the point, but also said that there might be benefits from collecting extra data elements, and/or collecting codes. How might the extra information lead to analysis of patient populations across different centers or regions, for example.

### **Upcoming Meetings**

- March 24, 2023, 1:00 to 2:00 pm (ET)
- April 28, 2023, 1:00 to 2:30 pm (ET)
- May 22, 2023, 1:00 to 2:30 pm (ET)
- June 23, 2023, 1:00 to 2:30 pm (ET)

## Attendance

- **Committee Members**
  - Rebecca Baranoff
  - Ashley Cardenas
  - Colleen O'Donnell-Flores
  - Karl Neumann
- **HRSA Representatives**
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- **SRTR Staff**
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- **UNOS Staff**
  - Nadine Hoffman
  - Sevgin Hunt
  - Eric Messick