OPTN Data Advisory Committee
Holistic Data Review Workgroup
Meeting Summary
January 27, 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 01/27/2023 to discuss the following agenda items:

1. Meeting Frequency and Updated Timelines
2. Review Updates to OPTN Data Subject Areas
3. Homework Discussion / Data standardization and ICD-10 codes

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

1. Meeting Frequency and Updated Timelines

EDM staff reviewed the meeting schedule and proposed eliminating the twice-monthly meetings in favor of a single monthly meeting, but extending the meeting time from one hour to one-and-a-half hours.

Specifically, staff proposed the following meeting dates and time and asked for Workgroup member feedback:

- 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)

The April, May, and June meetings would be extended to one-and-a-half hour meetings. The May meeting will be held on the 22nd to accommodate the May 29th Memorial Day holiday. The Workgroup members agreed to the proposed meeting dates.

EDM staff also proposed a revised timeline for project completion. It was mentioned that Committee leadership had suggested that the OPTN Board meeting in June may not be the best venue for initially sharing the comprehensive plan developed by the Workgroup. That is because of the amount of information typically presented during a Board meeting might cause the Workgroup's findings to get lost. EDM staff said that perhaps the alternative is to first socialize the results with the Executive Committee. It was proposed that the plan could be presented to ExComm sometime during October and November. Then, as part of the OPTN Board Meeting in December, the information could be included as part of the annual Committee deliverable. None of the Workgroup members raised concerns with the proposed timeline.

The Workgroup members were also encouraged to join the Committee's February 2, 2023 in-person meeting virtually, where an overview of the comprehensive plan would be presented and the upcoming work will be discussed.

2. Review Updates to OPTN Data Subject Areas

EDM staff opened the discussion with an overview of the interoperability standards and implementation specifications that occurred in 2009. As part of the Meaningful Use changes, CMS implemented rules for all entities to share electronic records. The federal government launched a program to incentivize the adoption of certified information systems with the necessary functionality and security to share clinical data. Opting out of the program meant entities could face CMS action in terms of reimbursements. The federal government launched the Interoperability Standards Advisory (ISA) website to help spread the purpose of the changes (https://www.healthit.gov/isa/isa-document-table-contents).

Among the materials available on the site, there are reference materials for documenting patient diagnoses codes. SNOMED CT and ICD-10 are identified. Several Workgroup members acknowledged their experience with ICD-10. A Workgroup member stated that because members' roles are often at the program level, and they may not be as aware of some of the hospital- or system-wide changes that occur.

The next topic the Workgroup members discussed involved their efforts to develop a current state document that can provide an overview of the distribution and the types of OPTN data that are available. Within OPTN data, quality is considered in different ways. Along those lines, EDM staff asked how do OPTN members uncover appropriate use cases for health data standards, and/or why data standardization is important in the Workgroup members' organizations? A member said that one reason standardization is important is to help programs that may be involved with multiple organs, and the program wants to ensure alignment across the differences in how those specific-organ programs are operating. Reporting outcomes and results consistently to identify performance metrics. Insurance companies also need consistency in reporting. Staff from SRTR pointed out that they had received questions that day about definition meaning and consistency.

The members reviewed the Data Subject Area information they have been working with and is found on the Committee's SharePoint site. Ways to drive data quality include using structured data collection, completeness of data, whether it is optional or required data, and the timeliness of the reporting. As a result of these different ways to consider it, data quality can be challenging to address. From the OPTN's perspective, the policy drives the "how" and "why" questions and information, and the OPTN forms drive the "what." Therefore, to best address data quality from all aspects, the Workgroup needs to be thinking about incorporating data standards. To ensure that the OPTN is collecting data in ways that align with the other parts of the healthcare industry, the worksheet has been updated to include links to the categories from the Health IT website previously mentioned.

As the Workgroup moves forward, it will be exploring the ICD-10 codes for their use in reporting mortality, morbidity, and outcomes. A Workgroup member asked how the existing OPTN diagnoses codes have been developed? Historically, the codes have been developed along with the policy language or changes they supported. That raises the question of whether there has been enough guidance provided on why the data are collected as they are, and whether that represents the most appropriate way to collect it.

Some of the data subject areas the Workgroup has been working on align with the diagnoses categories. There are opportunities to align some of them with standard diagnoses that have already been defined. What the Workgroup is asked to do is to go into a little deeper analysis of how codes can be used to map back to the OPTN data and how OPTN data can be standardized better from where it stands today.

EDM staff stated that the proposed exercise is intended to expand on how data are being reviewed and are there opportunities to improve data collection that lend themselves to implementing standards.

3. Homework Discussion

Summary of discussion:

A Workgroup member had submitted some questions to the spreadsheet related to data elements associated with Social Determinants of Health (SDoH), and whether the elements are relevant to the populations served by the OPTN and transplantation. It was explained that the SDoH-related codes are special codes that are a little different from diagnoses codes. However, more information is needed about what the codes are intended to do. It also remains to be seen the extent to which the codes will be used. EDM staff asked to let them know if members' organizations are considering the SDoH codes and how to leverage them.

For the next meeting, Workgroup members were asked to consider the benefits of using ICD-10/standard healthcare terms to improve diagnoses codes used in the OPTN data. They were also asked to consider how to leverage such codes to measure pre- and post-transplant outcomes. The following hyperlink to ICD-10 Resources on CMS' website was provided: https://www.cms.gov/Medicare/Coding/ICD10/Downloads/ICD10ResourcesFlyer20151007.pdf. The phases of the terminology part of the project were also discussed.

A Workgroup member asked for clarification on what the next steps are in terms of the data elements already considered as part of the Holistic Data Review and ICD-10 codes. EDM staff said that this is an opportunity to explore the use of ICD-10 codes / diagnoses codes as an example of a field that could be standardized. The comprehensive plan the Workgroup has been addressing still needs to address data scope, sequencing, as well as the other areas the group has been discussing. But, it is also useful to consider these areas more tactically and potentially address other components on the way. Diagnosis code is a good example.

Another concept for Workgroup consideration will be how to identify what data is critical for transplantation, and how best to prioritize collection of the critical data? Such information will be shared with the Workgroup for discussion purposes. A member suggested that it would be beneficial to have a comprehensive list of all data definitions and to make the list easily accessible to everyone. It was mentioned that because all OPTN data will be collected on OMB-approved collection instruments, there should be an opportunity to share the information without requiring system access to obtain it.

It was mentioned again that it is important for the Workgroup members to provide feedback on how the OPTN operates in order to improve all areas related to OPTN data. Therefore, members should feel free to share the challenges they experience along with what works well, so those areas can be addressed. A Workgroup member pointed out that ICD-10 and standardization will have a positive impact from a research perspective as well.

Upcoming Meetings

- 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)
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Attendance

- **Committee Members**
    - Rebecca Baranoff
    - Colleen O'Donnell-Flores
    - Krishnaraj Mahendraraj
    - Karl Neumann
- **HRSA Representatives**
    - Adriana Martinez
- **SRTR Staff**
    - Jon Snyder
- **UNOS Staff**
    - Brooke Chenault
    - Krissy Laurie
    - Nadine Hoffman
    - Sevgin Hunt
    - Robert Hunter
    - Eric Messick
    - Janis Rosenberg
    - Anne Zehner