

**OPTN Data Advisory Committee
Holistic Data Review Workgroup
Meeting Summary
August 26, 2022
Conference Call**

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

Introduction

The Holistic Data Review Workgroup (the Workgroup) met for the first time via GoToMeeting teleconference on 08/26/2022 to discuss the following agenda items:

1. Goals for Enabling Holistic Data Review
2. Discuss Deliverables
3. Discuss Timeline

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

1. Goals for Enabling Holistic Data Review

Enterprise Data Management staff outlined the expectations and intended impact of the Workgroup.

Data summary:

Where possible, the Workgroup will seek to:

- Reduce the burden of OPTN data collection
- Increase interoperability and efficiency in OPTN data collection
- Improve OPTN data quality
- Mature OPTN data management practices to actively manage the data throughout business/policy changes

Summary of discussion:

A representative from the Health Resources and Services Administration (HRSA) added that application programming interfaces (APIs) need to be considered within the scope of the Workgroup. They recommended that program-specific APIs should be updated at the same pace as OPTN data collection practice updates. Enterprise Data Management staff expressed concern that any policy requirements for adopting program-specific API updates could be difficult to enact as resources would have to come from the member organization to comply with the policy.

Next steps:

Staff will consider the Workgroup's feedback when reviewing the scope of the Workgroup.

2. Discuss Deliverables

Enterprise Data Management staff identified three areas of focus for OPTN data collection, maintenance, and organization.

Data summary:

Data

- Document the scope of OPTN data
- Inventory data domains/subject areas
- Identify critical data elements

People

- Identify OPTN Committee and UNOS staff stewardship for data domains
- Define responsibilities for stewards
- Determine how to codify the stewardship charge

Sequencing

- Assess current data risks
- Prioritize data domains by risk level
- Recommend data review project sequencing
- Determine if Policy 18 requires modification to close gaps contributing to Data Quality risk

Summary of discussion:

Data

The Chair expressed an interest in collecting more data beyond what is traditionally captured by the OPTN; they stated that there should be a parallel conversation alongside how the OPTN data collection practices can be improved that investigates how the OPTN can efficiently utilize data gathered from other sources for the same populations. Staff agreed with this idea, and added that there should be a list of ideas that stem from the Workgroup that do not fall into the initial phase of the Workgroup's efforts, but should be considered afterwards.

People

A member inquired if an organ group had been identified for the Workgroup at which to begin their data review. Staff responded that the Workgroup would be considering data elements by criticality rather than organ specific, noting that some elements would be easier to update across organ groups rather than addressing within each organ group. In addition, some data elements would be easier to assign Committee stewardship than others. This approach would also help introduce the concept of data quality stewardship to all Committees rather than assign a large number of elements to one Committee to begin. They emphasized that beginning with "horizontal" data review (data collected which is applicable to all organs) would help streamline the review process for "vertical" data review (data collected uniquely for one organ type).

A representative from HRSA asked if the principles of data collection and reporting would be reviewed by the Workgroup. Staff replied it was not immediately in the charge of the Workgroup, but again, should be considered for review after the first phase if the Workgroup wants to review all OPTN data. The HRSA representative requested, and staff agreed, that a process document should be considered for the standardization of a routine review process for all OPTN data collection practices. This idea was endorsed by multiple members.

Sequencing

Staff noted that part of sequencing would be collaborating with Committees to understand what the key areas of data usage are, as well as understanding who would be the steward responsible for assessing

that criticality. They added that part of that understanding of criticality would be assessing OPTN Policy 18 to determine if thresholds can be created for data quality. A member supported the idea of the Data Advisory Committee (DAC) reviewing Policy 18 for potential updates.

Next steps:

Staff will be considering the phases of the Workgroup, as well as the expected output of the Workgroup for each phase.

3. Discuss Timeline

Enterprise Data Management staff outlined the intended progression of the work done by the Workgroup.

Data summary:

Anticipated timeline is 7-9 months (14-18 meetings). Updates will continually be given through DAC full committee meetings.

The Code Standardization Project is expected to be done in tandem with this project.

Summary of discussion:

The Chair suggested there should be a period of “pilot testing” for the data review draft as it may manifest in different ways than the Workgroup envisioned. Staff responded that there were current processes in place for data review which could be examined and considered a pilot on a much smaller scope to identify areas that need improvement.

Next steps:

Staff will create a skeleton outline for which parts of the report should be discussed over the next 7-9 months according to the proposed timeline.

Upcoming Meeting

- September 9, 2022

Attendance

- **Committee Members**
 - Adrienne Goodrich-Doctor
 - Colleen O'Donnell-Flores
 - Jesse Schold
 - Krishnaraj Mahendraraj
 - Rebecca Baranoff
- **HRSA Representatives**
 - Adrianna Martinez
 - Chris McLaughlin
 - Shannon Dunne
- **SRTR Staff**
 - Bert Kasiske
 - Jon Snyder
- **UNOS Staff**
 - Courtney Jett
 - Eric Messick
 - Isaac Hager
 - Krissy Laurie
 - Kim Uccellini
 - Nadine Hoffman