OPTN Data Advisory Committee Meeting Summary January 13, 2020 Conference Call

Sandy Feng, MD, PhD, Chair Rachel Patzer, MPH, PhD, Vice Chair

Introduction

The OPTN Data Advisory Committee (DAC) met via teleconference on 01/13/2020 to discuss the following agenda items:

- 1. Policy Development Process Re-Orientation
- 2. Data Collection and New Data Review Processes
- 3. Overview of Current Data Collection Projects

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

1. Policy Development Process Re-Orientation

The DAC reviewed the OPTN Policy Development Process and what their role and perspective is when evaluating projects.

Summary of discussion:

A member questioned who, at UNOS, is making sure that the DAC is included during the early discussions for a proposed policy project. Committee staff explained that Data Governance will be working on processes to engage DAC in these conversations early and that Policy and Community Relations (PCR) staff will be diligent in referring a potential data collection project to Data Governance and DAC

A member inquired whether or not the DAC has the ability to initiate their own policy projects. Staff replied that the DAC could sponsor their own projects; however, short-term, most of their work is going to be collaborating with Subject Matter Expert (SME) committees on data collection projects. Long-term, DAC will be sponsoring the larger-scale reviews of existing data by subject area or domain. It was also mentioned that DAC-sponsored projects might follow a different process than policy development

A member inquired as to how efforts by the DAC may move forward. Staff explained that it is PCR's staff intent to give the DAC regular updates on projects.

2. Data Collection and New Data Review Processes

The DAC discussed the processes for reviewing new data collection projects and data review projects.

Summary of discussion:

A member mentioned that the map of the policy development process, including where the DAC needs to be consulted, was very helpful. It was also mentioned that the process would really come to life when there are projects involving data for the DAC to review.

A member questioned where the DAC is in regard to being able to run through the new steps for projects. Staff explained that the DAC could be using these new steps immediately with projects that are in their earlier stages.

Next Steps:

Discuss more in depth the review of existing data process.

3. Overview of Current Data Collection Projects

The DAC members reviewed projects involving data collection and distinguished between projects using new data collection tools and projects reviewing data.

Summary of discussion:

A member inquired as to where the collection of data related to non-static preservation was in the list of things being worked on or discussed. Staff explained that no committee has brought this to the DAC's attention. It was also mentioned that this data is important to have in the UNOS database and should be discussed by the DAC.

Upcoming Meetings

- February 10, 2020
- March 9, 2020
- March 27, 2020 (Chicago, Illinois)