OPTN Organ Procurement Organization Committee

Deceased Donor Registration (DDR) Review Workgroup

Meeting Minutes

July 16, 2019

Conference Call

Helen Nelson, RN, BSN, CCTC, CPTC, Workgroup Chair

# Introduction

The DDR Review Workgroup met via Citrix GoToTraining teleconference on 07/16/2019 to discuss the following agenda items:

1. Introductions
2. Background
3. Data Advisory Committee/Data Governance
4. Principles of Data Collection
5. Office of Management and Budget (OMB) Process
6. Deceased Donor Registration Form
7. Project Timeline
8. Conference Call Schedule
9. Open Discussion

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

## Introductions

### Summary of discussion:

Workgroup members introduced themselves by stating their job title, organization, and committee affiliation.

## Background

### Summary of discussion:

UNOS staff provided an overview of how this project originated. The OPO Committee meeting reviews and discusses member questions about the DDR during their bi-annual in-person meetings. UNOS staff provided a list of the question topics that were reviewed during the October 2018 meeting. These included the following:

* Cross clamp time for DCD
* Date and time authorization obtained for organ donation
* Other drug use (non-IV) ever
* Core cooling
* Chest x-ray
* Medical examiner/coroner
* Left/right lung bronchoscopy
* Heavy alcohol use

Following the discussion, the OPO Committee reached agreement that it is time for a comprehensive review of the DDR. They recognize that the data collected on this form is extremely important because it is used for data analysis by both the SRTR and OPTN.

UNOS staff also noted that this review will require collaboration with the Data Advisory Committee (DAC) and the UNOS Data Governance department. This collaboration will include identifying a framework and process for reviewing the DDR.

## Data Advisory Committee (DAC) and UNOS Data Governance Department

### Summary of discussion:

UNOS staff provided an overview of the roles of the DAC and Data Governance Department. The DAC has an overall responsibility to the Board of Directors for OPTN data collection, assessing data collection needs, and providing annual recommendations to the Board of Directors. The Data Governance Department is charged with setting and supporting data policies and standards, assessing and improving data quality, and standardizing data asset documentation.

UNOS staff provided an overview of previous work using a systematic assessment of data collection for both new and existing data elements. There was also a “standard of review” and checklist that was developed and used by the Thoracic Organ Transplantation Committee during a data collection proposal that was approved by the Board of Directors in June 2018. UNOS staff noted that there are components of this checklist that could be used by the Workgroup.

## Principles of Data Collection

### Summary of discussion:

UNOS staff reminded the Workgroup members of the following principles of data collection which were approved by the Board of Directors in 2006:

Institutional members must provide sufficient data to OPTN to allow it to:

a) Develop transplant, donation and allocation policies

b) Determine if Institutional Members are complying with policy

c) Determine Member-specific performance

d) Ensure patient safety when no alternative sources of data exist

e) Fulfill the requirements of the OPTN Final Rule

## Office of Management and Budget (OMB) Process

Summary of discussion:

UNOS staff provided a brief overview of the process for OMB approval of new or revised data collection. This process was established by the Paperwork Reduction Act (PRA) of 1995.[[1]](#footnote-2) UNOS staff noted that the Data Governance Department will be instrumental in helping the Workgroup and Committees with this process as the project moves forward.

## Deceased Donor Registration Form

### Summary of discussion:

UNOS staff highlighted the key sections of the DDR and noted that the Workgroup will also review the corresponding help documentation and data definitions.

## Project Timeline

### Summary of discussion:

UNOS staff provided a high-level overview of the timeline for this project. This included the approximate dates for public comment in 2020 with the goal of submitting recommendations to the Board of Directors in December 2020.

## Conference Call Schedule

Summary of discussion:

The Workgroup members agreed that monthly conference calls would be appropriate for this work while also acknowledging that additional conference calls might be required to complete this work according to the initial timeline.

## Open Discussion

### Summary of discussion:

The Workgroup Chair asked the members to engage with the individuals at their various organizations who work with the DDR on a regular basis as this project moves forward.

A member asked if the Workgroup charge was to revise or eliminate data elements and add data elements. UNOS staff noted that adding data elements is within the scope of this project as long as there is an appropriate justification is provided. The member also asked if UNOS staff had performed “data mapping” to see what data fields are in DonorNet® but are not in the DDR just to provide a baseline. UNOS staff noted that they would look into this request. The Workgroup Chair noted that if there was a way to automate the data entry then it could potentially reduce the burden of collecting additional data collection.

A member noted that it would be great to have common definitions for the data elements and to reduce redundancy within the system when information is collected within OPO’s electronic medical records and DonorNet.

UNOS staff noted that they will provide a copy of the DDR and data elements to the Workgroup.

# Upcoming Meetings (All conference calls)

* August 27, 2019
* September 17, 2019
* October 15, 2019
* November 19, 2019
* December 17, 2019

# Attendance

* **Workgroup Members**
  + Helen Nelson
  + Dan Disante
  + Jeff Trageser
  + Rick Hasz
  + Nicole Berry
* **HRSA Representatives**
  + Chris McLaughlin
  + Janet Kuramoto-Crawford
  + Jim Bowman
* **SRTR Staff**
  + Bert Kasiske
  + Ajay Israni
  + Nick Salkowski
  + Jon Snyder
* **UNOS Staff**
  + Robert Hunter
  + Kim Uccellini
  + Grace Acda
  + Catherine Monstello
  + Matt Cafarella
  + Randall Fenderson
  + Kimberli Combs
  + Matt Prentice

1. <https://it.ojp.gov/PrivacyLiberty/authorities/statutes/1289> [↑](#footnote-ref-2)