

**OPTN Organ Procurement Organization (OPO) Committee  
Deceased Donor Registration (DDR) Review Workgroup  
Meeting Minutes  
September 17, 2019  
Teleconference**

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

## **Introduction**

The Deceased Donor Registration (DDR) Review Workgroup met via teleconference on September 17, 2019 to discuss the following agenda items:

1. Clinical Information – Worksheet Trial
2. Next Steps

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

### **1. Clinical Information – Worksheet Trial**

UNOS staff reviewed the DDR Workgroup review worksheet with members and provided further instruction on how to utilize the tool while reviewing the DDR form.

#### Summary of discussion:

UNOS staff presented a demonstration of the review worksheet. The worksheet was added on SharePoint to allow members to provide their review responses in one central location. Workgroup members will use the tool to review and provide feedback for each data element using the checklist questions.

The Workgroup Chair asked members for their feedback about the spreadsheet. A member stated that there were some issues entering the information into the SharePoint site and that there were some difficulties in understanding how to use the application. UNOS staff provided instruction on how to access the document in SharePoint and enabling editing capabilities.

The Workgroup Chair suggested that a review of the worksheet would be helpful for workgroup members to better understand what would be ideal in the assessment of the DDR. UNOS staff reviewed each standard in the data evaluation tool by using the height data element as an example.

#### Purpose/Relevancy

UNOS staff explained that members should think about why the particular data element is being captured and all of the different reasons the data element is being collected should be detailed in this section.

The Workgroup Chair stated that height is used for a size matching element and that it can help in determining BMI and medication calculations.

SRTR staff added that in determining BMI from height and weight, certain risk assessment models are used and should be considered for this field as well.

#### Reliability

UNOS staff clarified that this section is to determine if the data is reliable and how it is being documented (manual/electronic).

The Workgroup Chair stated that for lung donors, there is a double check system for verification purposes for height in their hospital because patients could get screened off in error.

UNOS staff clarified that from the prospective of reliability, height would most likely be documented by someone with a clinical background which would help in evaluating how this information should be reported.

#### Data Definition

The type of feedback in this assessment would be detailed information on how the data element is being used and any additional feedback that would further clarify or make the data element precise. Workgroup members were encouraged to add any other information that should be added to make this data element clearer on how to collect it.

The Workgroup Chair asked that in regards to the definition piece, would it be appropriate to add in parameters for measurements? For height, it is believed that there could be parameters placed for this data element and justification could be provided for this. UNOS staff stated that this could be included in the feedback.

UNOS staff stated that for almost all of the data elements, there are status fields that provide options such as "N/A", "Not Done", "Missing", or "Unknown." Workgroup members should consider that when an unknown value is selected, is this an acceptable response and is there adequate instruction on when these values are appropriate? Are there scenarios where the height would not be available?

A member asked how this information would be entered if the patient was a double amputee. UNOS staff stated that this type of question is a great example of what to include in the evaluation of the data elements, especially in the definition piece. This type of question in particular could be referred to the Thoracic Committee for further input.

#### Availability, Burden, and Interoperability

UNOS staff stated that if there are any cases where this data element is not readily available, this feedback would be helpful in further assessing the data element.

#### Alternate Data Sources

UNOS staff stated that for this section, the workgroup should evaluate the best approach to reduce data entry burden among staff. Height would be a fairly easy field that could be transmitted via API (application programming interface).

#### Usability/Conformity

UNOS staff clarified that for this section, workgroup members should provide any information regarding whether the data element can be acquired elsewhere, such as another registry or other resource that is not related to the EMR. This category also addresses the organization of the fields on the form. If a data element is thought to fit better in a different section of the form, that information and rationale could be placed in this category.

UNOS staff added that if there were any recommendation to remove any of the data elements, there will be a parking lot set up to address and provide rationale for the removal of data elements. There was a column added for additional comments to include this.

The Workgroup Chair asked for an additional column to allow for additional comments in the case that there are certain data elements that workgroup members are having challenges in providing feedback. Workgroup members were asked to add their initials next to their comments since several members will be reviewing the same data elements.

UNOS staff then reviewed each standard in the data evaluation tool by using the serology data element as an example.

## **2. Next Steps**

UNOS staff shared next steps of the DDR Review project with workgroup members.

### Summary of discussion:

UNOS staff will provide an e-mail with detailed information of the evaluation process for the workgroup. Workgroup members were encouraged to reach out to UNOS staff if there are any issues with accessing the SharePoint document.

The meeting was adjourned.

### **Upcoming Meeting**

- October 15, 2019
- November 19, 2019
- December 17, 2019