

**OPTN Organ Procurement Organization (OPO) Committee
Deceased Donor Registration (DDR) Workgroup
Meeting Minutes
January 21, 2020
Conference Call**

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Introduction

The DDR Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 1/21/2020 to discuss the following agenda items:

1. Recap of 12/17 Conference Call
2. Finish Lifestyles Factors Review Discussion
3. Next Assignments

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

1. Recap of 12/17 Conference Call

Workgroup members reviewed the notes from the last call on 12/17/19.

2. Finish Lifestyles Factors Review Discussion

The Workgroup reviewed and discussed the Lifestyle Factors section of the Deceased Donor Registration (DDR) form.

Summary of discussion:

The Workgroup reviewed highlighted comments from the Lifestyle Factors section of the DDR.

Tattoos

The Workgroup discussed concern about the reliability of this data element. There was also discussion about whether a donor with a tattoo truly affects the decision about an organ offer from a donor. A member commented that the updated PHS Guidelines do not include tattoos as a risk factor.

The Workgroup Chair asked how this data element is used and why it needs to be collected on the DDR. She also noted that it might be important for tissue donation and less important for organ allocation.

The Workgroup recommend the remove of this data element from the DDR, if appropriate. The Workgroup members were reminded that as data elements are being evaluated for possible deletion from the DDR, there needs to be a determination about the impact on risk adjustments or other reasons for collecting the information.

According to the OPTN policy in effect on the date of referral, does the donor have risk factors for blood-borne disease transmission?

A member stated that at the time of referral, the OPO would not yet have all of the data they need to determine increased risk. In the meantime, organs are already allocated, placed, and transplanted by the time the DDR is completed.

A member stated that "on the date of referral" should be removed to make the question clearer.

UNOS staff clarified that this particular data element cascades from DonorNet to the DDR, therefore not requiring double entry.

History of Diabetes/Insulin Dependent

The Workgroup Chair stated that the only concerns raised about these data elements was that its availability is dependent upon the historian knowing this information. There was agreement that there should still be the option to select Unknown if this information cannot be obtained by the OPO.

History of Hypertension

A member raised a question about whether the information is documented history or family/historian reported. UNOS staff clarified that the help documentation states “documented history.”

Another member stated that the history of diabetes and hypertension are both collected in DonorNet and should cascade into the DDR.

If yes, method of control (History of Hypertension)

The Workgroup Chair stated that it would be helpful to know how many times “Unknown” is entered for this field. There was an understanding about the importance of this field, but it can be challenging for OPOs to determine if the donor has been able to control their hypertension with diet. From experience, when a donor has a history of hypertension they are usually on medication.

Another member agreed with the comment and stated that anecdotally, “Unknown” is often used. History of hypertension is usually reported by a family historian, who rarely know this information.

UNOS Research staff stated that they would look at this further to determine if this information is included in the SRTR models.

History of Cancer

The Workgroup agreed that this data field is fairly reliable and routinely captured.

A member stated that this field seems straightforward. The Workgroup agreed to keep this field as is.

Cancer Free Interval

The Workgroup Chair stated that this field is dependent on where the records can be obtained and on the reporting of a historian. There is also an issue with the definition of cancer free.

A member stated that the data could be inaccurate at times. UNOS staff asked the Workgroup members if there was a more objective data point that can be looked at to get this information if it is imperative to clinicians evaluating the organ.

The Workgroup Chair stated that if there is a history of cancer, the hospital staff have to search for the medical records. When the information is not available, clinical judgement has to be made.

The Workgroup decided to discuss this data field in further detail to determine next steps.

Cancer at Time of Procurement (intracranial, extracranial, skin)

The Workgroup Chair asked why basal and squamous cell carcinoma are included when they are not rule outs for organ donation. These types of skin cancers are not the same as melanoma.

UNOS Research staff clarified that in cases where at least one organ was recovered for the purpose of transplant, this data may help analyze post-transplant outcomes of donors with specific types of history.

A HRSA representative stated that from a VCA perspective, this data may be useful to that community.

UNOS Research staff asked the Workgroup if there was a need for an Unknown option. A member stated that there have been instances where cancer was not identified until an autopsy was performed.

A member stated that the Unknown field has been used during circumstances when a biopsy was unclear. The Workgroup decided to keep the Unknown field to this section.

Chagas History

This field was added to the DDR in 2015 following a recommendation from the Ad Hoc Disease Transmission Advisory Committee (DTAC). The field is required and Unknown can be selected.

A HRSA representative stated that the DTAC is interested in the Chagas history due to the sporadic Chagas that can become present in a recipient and it helps determine if the Chagas is from the donor or not.

The Workgroup agreed to discuss this field in further detail to determine next steps. UNOS staff will check if this information is being collected in DonorNet.

TB History

The Workgroup Chair stated that not all OPOs test for this. UNOS Research staff asked if there would be any difference in consistency in testing or reporting. The Workgroup Chair stated that for history, additional information on if the patient was treated and how they were diagnosed would be needed.

A member stated that what is more important is whether there is a documented history or not.

A HRSA representative stated that from the DTAC's perspective, this is information that would be valuable to collect.

The Workgroup agreed to discuss this field in further detail to determine next steps. UNOS staff will check if this information is being collected in DonorNet.

Next Steps

- The Workgroup will assess and follow up on data elements that were flagged in further detail in upcoming discussions.

3. Next Assignments

Summary of discussion:

The Workgroup will begin working on new assignments that will review the Organ Recovery section of the DDR.

There was no additional comments. The meeting was adjourned.

Next Steps

- The Workgroup will work on their assignments in preparation for the February 18, 2020 conference call.

Upcoming Meeting

- February 18, 2020