

**OPTN Organ Procurement Organization Committee  
Deceased Donor Registration (DDR) Review Workgroup  
Meeting Summary  
May 19, 2020  
Conference Call**

**Helen Nelson, Workgroup Chair**

## **Introduction**

The OPTN DDR Review Workgroup (the Workgroup) met via Citrix GoToTraining teleconference on 05/19/2020 to discuss the following agenda items:

1. Procurement and Authorization Review Discussion
2. Next Assignments

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

### **1. Procurement and Authorization Review Discussion**

The Workgroup discussed the following questions in the DDR's Organ Recovery section:

- Medical examiner/Coroner
- Was the patient declared legally brain dead
- Cardiac arrest since neurological event that led to declaration of brain death
  - If yes, duration of resuscitation
- Did the patient have written documentation of their intent to be a donor
  - If yes, indicate mechanisms
  - Was this authorization based solely on this documentation
- Did the patient express to family or others the intent to be a donor
- Date and time of pronouncement of death (complete for brain dead and DCD donors)
- Date and time authorization obtained for organ donation

#### Summary of discussion:

A member inquired about the title including the word "procurement." A member stated that the "Cardiac arrest since neurological event that led to declaration of brain death" question would fit into a procurement section. Members agreed that this section should be split into two sections: (1) authorization and (2) procurement.

Members suggested moving the questions regarding cardiac arrest, duration of resuscitation, and pronouncement of death into the procurement section. A member stated that this procurement section would flow better either as its own section before the organ recovery section or by adding these questions to the organ recovery section.

#### *Medical examiner/Coroner*

United Network for Organ Sharing (UNOS) staff explained that this field might be a holdover from when the DDR was required to be completed on potential donors that have consented to donation, not just those donors whose organs were recovered for the purpose of transplant. UNOS staff inquired about the relevancy of this data element.

A member stated that it appears this question is trying to capture whether the medical examiner was involved, so then the response options could be “yes – involved and consented” or “no, not involved”. Otherwise, if the medical examiner refused to consent for organ donation, the OPO is not required to complete the DDR since it does not meet the policy definition of a “deceased donor.”

A member stated that the “medical examiner refused consent” option should open a list of organ options so that data can be collected on which organs were not released by the medical examiner. It was also stated that “medical examiner limitations” could be used instead of “refused.” Another member mentioned that there should be a disposition code if the organs are refused and that this data may be captured in those codes. A member also mentioned that this data could get complicated if the medical examiner/coroner accepts organs for transplant but does not release them for research purposes.

UNOS staff inquired about the use of this information and whether it still needs to be collected. A member commented that having this national data would be important and that the OPTN should collect this data in a similar way as the Association of Organ Procurement Organizations (AOPO). He also noted that the data would need to be more granular as mentioned previously to know whether the medical examiner/coroner turned down the donor or just refused certain organs.

A member noted that this exact question is in the Death Notification Registration (DNR). A member also stated that this cascades into the DDR from the DNR when the deceased patient becomes a donor. Members agreed that the question should be the same for both forms.

A member suggested this question on both the DDR and DNR:

Did the medical examiner/coroner restrict or limit the number of organs for transplant?

- Yes
- No
- Not applicable

*Was the patient declared legally brain dead?*

A member inquired about why “legally” was included in the question since states have different brain death laws. The member questioned how many patients were declared illegally dead then became organ donors.

A member inquired about the subset of cardiac arrest questions attached to this question. A member stated that donation after circulatory death (DCD) donors in different Maastricht categories can arrest after declaring them brain dead; however, the recovery of the organs would still continue as if the donor was declared brain dead and there isn’t a 5 minute waiting time. Another member expressed concern that this question isn’t clear as to whether the cardiac arrest happened before or after declaration of brain death and that, since it’s unclear, it’s probably not capturing the data we want.

Another member stated that this question might be trying to capture the uncontrolled cases, for example, where a deceased patient experiences some event after declaration of death that inhibited the actual normal process of donation. Another member noted that it’s not clear what the intent of this question is.

A member suggested three possible purposes for this question:

- To capture uncontrolled DCD donations, that can be from brain dead donors or just cardiac arrest (the different Maastricht categories)

- To capture how many times deceased patients did not make it to the operating room because they arrested and couldn't be resuscitated
- To capture the number of patients that were successfully resuscitated but then experienced organ damage

A Scientific Registry of Transplant Recipients (SRTR) member mentioned that this question is used in the donor yield models. SRTR's understanding of this question is that there was a cardiac arrest event during this terminal event and whether it was before or after declaration doesn't really matter. SRTR would then use this data to model if there is an increased risk of non-use of the organ due to cardiac arrest during that hospitalization event. SRTR members explain that there is a lower chance of organs being used if the donor experiences cardiac arrest and that cardiac arrest could potentially result in a DCD donor.

Members agreed that this section of questions should all be their own questions, not subsets of each other, and that these questions could be asked in a clearer way.

A member suggested building this section of questions based on the information members want to know, which is:

- How many brain dead donors are recovered as DCD?
- Are we doing donor management well?
- Was there cardiac arrest after brain death? Did it effect the organ yield?
- If there's an injury, where do we start this pathway – the event or after hospitalization?

*Did the patient have written documentation of their intent to be a donor?*

A member inquired about whether the type of documentation of intent is important. UNOS staff explained that they do get questions about child donors and what registry they came from.

UNOS staff mentioned that the Organ Procurement Organization (OPO) Committee proposed revisions to this question in the DNR and those revisions will be implemented in early 2021. The current question in the DNR is "Has authorization been obtained for organ donation?" and the responses are yes, no, authorization not requested, or registry - yes. The Committee determined that this question was trying to capture two different pieces of information and recommended that the question be separated as shown below:

- Did patient legally document decision to be a donor? – Yes or No
- Has the authorization been obtained for organ donation?
  - Yes - first person authorization,
  - Yes, hierarchy utilized
  - No, declined
  - No, not requested

A member recommended that changes to the DDR be consistent with the upcoming changes to the DNR. A member inquired about what the term hierarchy utilized meant. UNOS staff explained that there was first person authorization and then the authorization went to hierarchy, which is the list of persons who are legally entitled to make an anatomical gift.

A member inquired whether this form is capturing whether the donor comes from the state registry or the Donate Life America registry. A member explained that OPOs are capturing this data and that it helps Donate Life America analyze which states are adding their registrations into the national registry.

Members agreed that this field will need to be reworked and aligned with the DNR.

## **2. Next Steps**

The Workgroup Chair will further discuss the revisions to this section with UNOS support staff and the Workgroup will finish their discussion of the section during its next meeting.

### **Upcoming Meetings**

- June 16, 2020