

**OPTN Organ Procurement Organization Committee
Deceased Donor Registration (DDR) Review Workgroup
Meeting Summary
June 16, 2020
Conference Call**

Helen Nelson, Workgroup Chair

Introduction

The OPTN DDR Review Workgroup (the Workgroup) met via Citrix GoToTraining teleconference on 06/16/2020 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 reviewed their previous discussion and agreement to make changes to the following questions:

- 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:

Workgroup members agreed to remove "procurement" from the title of this section and move the following questions to the DDR's Organ Recovery section:

- Cardiac arrest since neurological event that led to declaration of brain death
 - If yes, duration of resuscitation
- Date and time of pronouncement of death (complete for brain dead and DCD donors)

Medical examiner/Coroner

Workgroup members agreed to maintain this question and align it with Association of Organ Procurement Organizations (AOPO) data collection and the OPTN Death Notification Registration (DNR) form.

SRTR staff mentioned that a researcher had obtained this data and incorrectly interpreted this question to mean that the medical examiner/coroner actually gave authorization for transplant. Workgroup

members responded that, while this may cause confusion for those utilizing the data, OPO staff are clear about how to input this data.

A Workgroup member stated that this seems to be a two-part question: (1) involvement/reporting to the medical examiner/coroner and, (2) whether the medical examiner/coroner issued any restrictions for organ donation. A member suggested asking whether the medical examiner/coroner was “notified”, instead of “involved”.

A Workgroup member expressed concern about confusing cases that medical examiners/coroners accepted and cases that they declined by just asking whether the medical examiner/coroner was notified. A Workgroup member mentioned that it seems this question is trying to capture whether the medical examiner/coroner took jurisdiction over the case.

A Workgroup member also inquired about the importance of including the question regarding medical examiner/coroner involvement, and instead just asking about restrictions. A member mentioned that if one is trying to understand the donor pool and how many cases fall under the medical examiner/coroner jurisdiction, then keeping the involvement question would be helpful.

A Workgroup member inquired whether the DDR should ask the same question about involvement as the DNR. A member explained again that it also captures cases that don’t fall into the medical examiner’s/coroner’s jurisdiction. It was also noted that the data from the DNR cascades to the DDR.

The Workgroup agreed to split this question into three in order to capture the data they want:

- Did you notify the medical examiner/coroner?
 - Yes
 - No – skip 2 questions below
- If yes, did the medical examiner/coroner accept the case?
 - Yes
 - No
- If yes, were there any restrictions?
 - Multi-select menu of all organs

Was the patient declared legally brain dead?

The Workgroup decided not to make any changes to this question.

Cardiac arrest since neurological event that led to declaration of brain death

The Workgroup decided to update the help documentation regarding this question and improve the definition once it’s moved to the organ recovery section.

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

The Workgroup decided to align this question with the upcoming changes to the DNR:

- Did patient legally document their decision to be a donor?
 - Yes
 - No
- Has authorization been obtained for organ donation?
 - Yes, first person authorization
 - Yes, hierarchy utilized
 - No, declined

- No, not requested

A Workgroup member inquired about the purpose of the question – “Was this authorization based solely on this documentation?” A member agreed that the intent is to know if authorization had been obtained, not if the documentation was the “sole” reason for authorization.

A Workgroup member mentioned that, even if a patient has first person authorization, they would still check “no” to the authorization being based solely on this documentation. The member explained that there are multiple organ procurement organizations (OPO) that don’t recognize first person authorization for donation after cardiac death (DCD) donors and, instead, fill out a second DCD authorization form.

Workgroup members agreed to remove this question from the DDR.

Did the patient express to family or others the intent to be a donor

Workgroup members agreed that they don’t see a purpose for this question and recommended that it be removed from the DDR.

Date and time authorization obtained for organ donation

A Workgroup member inquired about the importance of this information. A member explained that this data could be used to understand how long families wait for death to occur, especially with brain death, and then use this for process improvement.

A Workgroup member questioned whether the OPTN collects the patient’s admission or referral date and time. How could centers analyze process improvement if data from the beginning of the process isn’t collected? United Network for Organ Sharing (UNOS) staff explained that this data is collected in DonorNet but not on the DNR.

A Workgroup member expressed concern about the appropriateness of using these two dates and times to infer process improvement. Members explained that the “Date and time of pronouncement of death” could have to be used for determining when donor management was initiated.

2. Next Steps

- Review final two more sections of the DDR – still targeting January 2021 public comment.
 - Organ Disposition section
 - Donor Information section
- Find replacements for Workgroup members rotating off
- Reach out to organ-specific committees regarding workgroup recommendations and seek feedback on questions identified by the workgroup.

Upcoming Meetings

- TBD