

**OPTN Organ Procurement Organization Committee
Deceased Donor Registration (DDR) Review Workgroup
Meeting Summary
September 24, 2020
Conference Call**

Jeff Trageser, Workgroup Chair

Introduction

The OPTN DDR Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 09/24/2020 to discuss the following agenda items:

1. Donor Information Discussion
2. Organ Dispositions Discussion

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

1. Donor Information Review Discussion

Summary of discussion:

Name

The workgroup agreed to update the help documentation to provide general direction for OPOs when the donor identity is unknown ("John Doe"). This could include the use of the hospital alias.

Home city, state, and zip code

Workgroup members discussed the lack of an "unknown" option for this data element. There was concern about OPOs using inconsistent processes for completing these fields, such as the use of the donor hospital location. UNOS staff commented that using the donor hospital location could affect the quality of data, such as analyzing social economic status.

The workgroup recommended adding an "unknown" option and modifying the help documentation

Citizenship

Workgroup members noted that the DDR is the only form that allows for an "unknown" option for the citizenship information. Members also noted that most OPOs do not ask for proof of citizenship status. Members inquired about whether it is important to collect this information, particularly if the data is not reliable and accurate.

Causes of death, mechanism of death, and circumstances of death

The workgroup discussed whether the responses affected the SRTR expected yield models. One member noted there are many ambiguities and OPOs probably do not enter these in a consistent way. For example, an accidental overdose might be interpreted a number of ways by different OPOs (natural causes vs. non-MVA).

The workgroup members agreed these would require a comprehensive review and revisions as part of a separate project.

2. Organ Dispositions Review Discussion

Summary of Discussion

Organ

The workgroup recommended updating the help documentation – replace “consent” with “authorization”

If DCD, date and time (organ) recovered/removed from donor

The workgroup members inquired as to why this is not collected for brain dead donors. UNOS staff noted that this data element was added when DCDs were becoming common practice. There was some discussion about why this information was needed, such as calculating warm ischemia time (WIT). It was noted that cross clamp time and flush should be used to calculate WIT.

Recommendation: Remove from the DDR if possible. If not, remove “if DCD”

Recipient

This data element cascades from DonorNet. No recommended changes.

Social security number

The workgroup agreed that the use of the social security number is being used less often for identification purposes and OPOs and transplant centers typically utilize the name and waitlist ID number.

Recommendation: Remove from the DDR

Transplant center

No recommended changes

Reason code (for organs with no authorization to recover)

The workgroup members noted that often times there are more than one appropriate response. One member noted concern about the reliability of the information because of inconsistent practice. This could be contributed to OPOs trying to identify the best “broad” category to use. For example, if a donor has a marginal heart this could be classified as poor donor quality instead of trying to overthink the categories such as history of previous cardiac surgery versus severe cardiac disease.

The workgroup also briefly discussed authorization and whether OPOs get authorization for each individual organ or is it a general authorization for all organs.

Reason organ not transplanted

The workgroup had a similar discussion and noted that multiple responses could apply to a particular donor. Again, this leads to inconsistent practices and interpretation when completing the DDR.

The workgroup members noted that these cascade from other forms and recommend that both the “reason code” and “reason organ not transplanted” require a comprehensive review and revisions as part of a separate project.

Upcoming Meetings

- October 8, 2020

Attendance

- **Workgroup Members**
 - Jeff Trageser
 - Meg Rogers
 - Deb Cooper
 - Sue McClung
- **HRSA Representatives**
 - Jim Bowman
 - Vanessa Arriola
 - Marilyn Levi
 - Adriana Martinez
- **SRTR Staff**
 - Bert Kasiske
 - Jon Snyder
 - Andrew Wey
- **UNOS Staff**
 - Robert Hunter
 - Rebecca Brookman
 - Darby Harris
 - Peter Sokol
 - Sarah Taranto
 - John Rosendale
 - Alice Toll
 - Kimberly Uccellini
 - Nicole Benjamin
 - Carly Engelberger
 - Meghan McDermott
- **Other Attendees**
 - Luis Dorame