

**OPTN Living Donor Committee
Living Donor Data Collection Workgroup
Meeting Summary
October 7, 2022
Conference Call**

Introduction

The Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 10/07/2022 to discuss the following agenda items:

1. Living Donor Data Element Review

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The Workgroup reviewed data elements on the Living Donor Registration (LDR) and Living Donor Follow-up (LDF) forms.

Summary of discussion:

Data Element: Cause of death (LDR)

A member asked if the response options are consistent with what is utilized for transplant candidates and recipients. The member stated that a holistic review of data should include ensuring consistency among data elements across different domains as much as possible.

It was noted that this data element is separate from the living donor death reporting requirement per *Policy 18.5: Reporting of Living Donor Events*.

Another member stated that homicide and suicide may not be necessary options for purposes of the LDR due to its required submission at time of discharge. UNOS research staff noted that homicide and suicide have been submitted as cause of death on the LDR prior.

A member stated that aligning the response options with the perioperative period (i.e. related to the donation surgery) may make sense. Another member agreed that the response options for this data element on the LDR should be very specific to surgical related deaths.

An SRTR representative noted that the Living Donor Collective has data linkages to the national death index. UNOS research staff noted that the OPTN also has data linkages, such as with Centers for Medicare and Medicaid Services (CMS) end-stage renal disease (ESRD) data. A member stated that any living donor death identified through data linkages should be reported back to the transplant program.

Another member stated that the most relevant response options related to the donation/surgery event are already included.

A member stated that 'malignancy' as a response option may not be a relevant response option in the LDR.

Data Element: Cause of death (LDF)

A member suggested aligning response options with what the Centers for Disease Control and Prevention (CDC) utilizes. The member stated that response options should be consistent for transplant candidates and recipients as well.

An SRTR representative stated that the response options that specify 'donation/surgery related' may not be relevant options one to two years post-donation.

Data Element: Non-autologous blood administration (LDR)

Another member asked whether the data element needs to specify non-autologous versus autologous. A member agreed that it is important to know whether the living donor received any blood administration. The member noted that the risk associated with autologous blood is less, which may be why the data element originally focused on non-autologous blood administration. The member stated that 'whole' blood should be added as a response option. Another member suggested the addition of an 'other, specify' category. The member noted that the 'other, specify' category could be used for blood administration options such as whole, cryo, and factor eight. The member noted that the primary blood administration options are already included.

Data Element: Date of last contact or death (LDF)

A member stated that date of last contact or death is important information. The member added that data on lost-to-follow-up is also important, as date of last contact may not be indicative. Another member agreed and stated that one of the most common reasons for lack of living donor follow-up is due to lost-to-follow-up.

Data Element: Most recent donor status since (LDF)

It was noted that if a donor is lost-to-follow-up, this data element provides an option which specifies the transplant program was unable to contact the living donor.

A member stated that 'not seen' does not appear to be a relevant option. The member explained that response option is confusing. UNOS research staff noted that 'not seen' may be used by transplant programs who do not have a planned follow-up with the living donor during a certain follow-up reporting timeframe, but the living donor is not lost-to-follow-up. UNOS research staff explained that entering 'not seen' allows for the next LDF form to be generated. The member suggested that the LDF should auto-generate if the living donor is alive or lost-to-follow-up, but not if death was indicated. Members agree that the LDF forms should be available to transplant programs on-demand. Another member suggested the timeframes to submit the LDF forms may benefit from being expanded in an effort to collect as much data as possible.

Another member suggested to modify the 'not seen' response option to state 'living: not seen'. It was noted that entry of that response option would make the assumption that the living donor is alive, which may not be accurate data. A member suggested to modify the 'not seen' response option to state 'unknown'. The member suggested an additional response option to indicate that the transplant program intends to continue to contact the living donor.

Another member stated that the specifications within each response option may not add necessary information.

Discussion: Living donor follow-up data collection

A member stated that the generation of LDF forms should support transplant programs to make a continual effort to follow-up with living donors. An SRTR representative noted that the Living Donor Collective was created to help relieve transplant programs of the responsibility of following up with

living donors. The SRTR representative noted that the Living Donor Collective follows-up with individuals who were evaluated for living donation but did not go on to donate in order to establish a control group. Another member asked for more information on the laboratory values that are collected within the Living Donor Collective follow-up data collection. The SRTR representative stated that living donor follow-up will need to be a collaborative approach.

Next steps:

The Workgroup will continue reviewing data elements on the LDR and LDF forms.

Upcoming Meeting

- November 18, 2022 (teleconference)
- December 16, 2022 (teleconference)

Attendance

- **Workgroup Members**
 - Angele Lacks
 - Jesse Schold
 - Nahel Elias
 - Paul MacLennan
 - Stevan Gonzalez
 - Vineeta Kumar
- **HRSA Representatives**
 - Adriana Martinez
 - Mesmin Germain
- **SRTR Staff**
 - Ajay Israni
 - Bert Kasiske
 - Katie Siegert
- **UNOS Staff**
 - Cole Fox
 - Isaac Hager
 - Jen Wainright
 - Kim Uccellini
 - Lauren Motley
 - Lindsay Larkin
 - Meghan McDermott
 - Samantha Weiss