

**OPTN Living Donor Committee
Living Donor Data Collection Workgroup
Meeting Summary
August 31, 2022
Conference Call**

Introduction

The Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 08/31/2022 to discuss the following agenda items:

1. Living Donor Data Collection Recap
2. Living Donor Data Element Review

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

1. Living Donor Data Collection Recap

Since the last Workgroup meeting, the OPTN Living Donor Committee (the Committee) has been discussing the future of living donor data collection. The Committee will submit a report to the OPTN Board of Directors that will include justification for collecting data on living donors, an initial review of existing data on the OPTN Living Donor Registration (LDR) and Living Donor Follow-up (LDF) forms, and recommendations regarding living donor data collection.

2. Living Donor Data Element Review

The Workgroup reviewed data elements on the LDR and LDF forms.

Summary of discussion:

Data Element: Date of Initial Discharge (LDR)

A member stated that if a living donor is in need of rehabilitation, it often occurs at a different hospital than where the donation occurred. The member asked whether date of initial discharge and date of rehabilitation discharge should be captured separately. The member noted that rehabilitation for living donors is very rare. A member responded that adding an additional element to note rehabilitation discharge date may be too burdensome given the rarity of the event. Another member agreed and stated that it is reasonable to keep the data element as is if it captures total length of stay. The member stated that the data element is worded appropriately, it collects objective data, and provides important information.

A member asked whether the word 'initial' is needed. The member explained that the *date of discharge* is established as total length of stay. UNOS staff stated that the word 'initial' may be included in this data element due to consideration of the scenario where a living donor may be readmitted a couple days after the initial discharge. UNOS staff added that the word 'initial' was added to clarify that the date entered should document the first discharge date, if there are subsequent readmission and discharge dates.

Another member suggested that this data element could be modified to state *date of discharge from index hospitalization for donor nephrectomy*.

The Workgroup agreed that this data element should be modified to have a clearer title.

Data Element: Donor Status (LDR)

A member suggested to modify this data element to be a single selection if the living donor died. The member stated this may reduce burden so that entry of this element is only necessary if the living donor died, rather than entering this data element for every living donor. The member stated that this modification could connect to the *cause of death* data element. UNOS staff noted that while the current data entry has some burden, it provides clear and accurate information on whether the living donor is living or deceased. UNOS staff noted that modifying the data element to only require entry if the living donor died results in the assumption that the living donor is living which is not as reliable. The Workgroup agreed with the provided context for the current data collection mechanism. Another member agreed that data collection should continue to be proactive and strive to have no missing entries.

Staff added that, in the rare event that a living donor does die during this timeframe, the future forms will not generate.

A member asked whether there is logic in the system that if the option 'living' is selected, then the *cause of death* data element does not appear. The member stated that the *cause of death* data element should only appear if 'dead' is selected.

Another member responded that loss to follow-up should be added as a third option. A member responded that the LDR is filled out at time of initial discharge from the hospital. The member suggested that the loss to follow-up option be addressed on the LDF form.

HRSA representative asked whether there is utility in collecting data on complications that living donors may be experiencing. The Workgroup noted that there are data elements collected on the LDR and LDF related to various complication considerations, and the Workgroup will review these data elements as their granular review of data continues. The Workgroup noted that data elements related to 'other complications' for living vascularized composite allografts (VCA) donors may be important in the future as the VCA field begins to evolve.

Data Element: Date Last Seen or Death (LDR)

A member asked about the difference between *date last seen or death* data element and *date of initial discharge* data element. Another member suggested that this data element might be clearer if it was modified to state *date of discharge or death*. Another member agreed and stated that the *date last seen* portion of the data element is more relevant for the LDF forms.

A member stated that the *Post-operative Information* section of the LDR is not clear. The member added that this data element specifically would benefit from modifications to clarify the necessary data entry.

Another member stated that if the LDR already collects *date of initial discharge*, then no additional information is gleaned from *date last seen*. The member stated that a living donor may return to the transplant program shortly after the donation surgery for an ancillary reason. The member stated that this may then be interpreted as the *date last seen*, however that is most likely not the original intention of this data element. UNOS staff explained that if a living donor returned to the transplant program after discharge, that information should be collected on the LDF. The member suggested that this data element could potentially be removed.

The Workgroup further discussed the organization of data elements within the *Post-operative Information* section on the LDR. A member suggested the data elements in this section should be

organized as follows, *date of discharge, donor status*, if dead is selected for donor status, then *cause of death*.

HRSA staff asked whether the living donor data collection forms should collect the last time the transplant program communicated with the living donor. HRSA staff explained that the transplant program may not have seen the living donor, but communicated with them via telephone. A member responded that understanding lost to follow-up is very important and data elements on the LDF may address this.

Next steps:

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

Upcoming Meeting

- October 7, 2022

Attendance

- **Workgroup Members**
 - Angele Lacks
 - Heather Hunt
 - Jesse Schold
 - Macey Levan
 - Nahel Elias
 - Paul MacLennan
 - Stevan Gonzalez
 - Vineeta Kumar
- **HRSA Representatives**
 - Adriana Martinez
 - Arjun Naik
 - Chris McLaughlin
 - Shannon Dunne
 - Marilyn Levi
 - Vanessa Arriola
- **SRTR Staff**
 - Bert Kasiske
 - Krista Lentine
- **UNOS Staff**
 - Brooke Chenault
 - Cole Fox
 - Courtney Jett
 - Isaac Hager
 - James Alcorn
 - Jen Wainright
 - Lauren Motley
 - Lindsay Larkin
 - Meghan McDermott
 - Nadine Hoffman
 - Samantha Weiss