

**OPTN Living Donor Committee  
Data Collection Workgroup  
Meeting Summary  
January 20, 2023  
Conference Call**

## **Introduction**

The OPTN Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference 01/20/2023 to discuss the following agenda items:

1. Review of Living Donor Feedback Form

The following is a summary of the Workgroup discussions.

### **1. Review of Living Donor Feedback Form**

The Workgroup reviewed data elements on the Living Donor Feedback form and provided their thoughts and suggestions.

#### Summary of discussion:

##### *Data element: Organ types*

A member asked if it is possible to know which kidney is being donated when this form is being filled out. Ultimately, members felt that that clarification is better left on the Living Donor Registration form, as it is extraneous information to have prior to surgery and may not be known at time of form completion. The Workgroup recommended streamlining the data element responses to simply collect which organ type is being donated. The Workgroup recommended that the Living Donor Feedback form does not need to collect whether the living donor is a domino donor or a non-domino donor. The Workgroup suggested the Living Donor Registration form can collect that information.

##### *Data element: Is the donor participating in any KPD program?*

The Workgroup previously recommended broadening this data element to include all paired donation programs, not just kidney paired donation (KPD).

A member asked if this data element captures paired donation within KPD programs, or if it is supposed to capture paired donation within transplant programs as well. Staff clarified that the intent of the data element is to capture any kidney paired donation regardless of if it occurred within a KPD program or an internal transplant program exchange. Members suggested to remove the word “program” to reduce any confusion, as this data element intends to capture any paired exchange that occurs.

Another member asked if a follow-up data element should be added to indicate whether the living donor is participating in a regional or national paired donation program. A member responded that that information may not be known at this point in time. Another member stated that it may be difficult to define what entails a regional paired donation program. Staff suggested this could be included on the Living Donor Registration if it is determined to be a relevant and necessary data element.

A member asked if the responses should differentiate living donors who are part of a voucher program. The intention of the voucher program is for a living donor to come forward and donate an organ in

exchange for a voucher for a future organ transplant for somebody else, typically a family member or close friend.

Members felt that instead of collecting voucher-related data on the Living Donor Feedback form, it may be better placed on the Living Donor Registration form. A member noted that data coordinator fills out the Living Donor Follow-up forms, and would likely not be aware of where to look for information to confirm this after donation. The Workgroup will continue to discuss the potential of collecting data on living donors who receive vouchers, and the appropriate placement of such a data element.

*Data elements: Living donor recovery procedure aborted after donor received anesthesia OR living donor organ recovered but not transplanted?*

Members felt that the data element should be separated to avoid any confusion, since they are two distinct situations. A member suggested separating it further to ask whether there was a recipient or living donor issue that prevented surgery from proceeding or from the organ being transplanted. Members recommended that the data element should be broken down into multiple parts and rewritten in simpler language to prevent confusion. HRSA staff noted that if an organ was recovered and not transplanted, then that would not qualify as an aborted procedure.

The Workgroup reviewed free text analyses for this data element related to liver and kidney. A member noted that while *other, specify* responses are difficult since they require free text analysis, they supported keeping the response options as is since the free text responses are sparse and there does not appear to be a logical way to collate them into one category that would be meaningful.

Next steps:

The Workgroup will continue to discuss the need to potentially add or remove data elements to the Living Donor Feedback form.

**Upcoming Meetings**

- February 17, 2023 (teleconference)

## Attendance

- **Workgroup Members**
  - Angele Lacks
  - Aneesha Shetty
  - Jesse Schold
  - Jon Snyder
  - Paul MacLennan
  - Macey Levan
  - Nahel Elias
  - Stevan Gonzalez
  - Vineeta Kumar
- **HRSA Representatives**
  - Adriana Martinez
  - Mesmin Germain
  - Jim Bowman
  - Shannon Dunne
- **SRTR Staff**
  - Krista Lentine
- **UNOS Staff**
  - Carol Covington
  - Eric Messick
  - Jen Wainright
  - Kim Uccellini
  - Meghan McDermott
  - Samantha Weiss
  - Stryker-Ann Vosteen