

**OPTN Living Donor Committee  
Living Donor Data Collection Workgroup  
Meeting Summary  
February 17, 2023  
Conference Call**

## **Introduction**

The OPTN Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 02/17/2023 to discuss the following agenda items:

1. Continued Review: Living Donor Feedback Form

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

### **1. Continued Review: Living Donor Feedback Form**

The Committee continued to review the Living Donor Feedback form and discussed potential data element additions to this form.

#### Summary of Discussion:

A member suggested the name of the Living Donor Feedback form be modified to be titled Living Donor Identification form. Workgroup members concurred that the title of the form is misleading and can cause confusion.

A member stated that granular location data on living donors will help inform analyses and development of evidence-based policy. The member acknowledged that HRSA may need to determine if additional oversight is needed over living donor address data due to privacy concerns for research purposes. A member suggested making the nine-digit zip code a required field on the form. Another member stated that residential address could be mapped to input the nine-digit zip code since individuals do not often know their nine-digit zip codes. Staff noted that the Living Donor Registration (LDR) does collect address and zip code. Members noted that the "address" data element on the LDR should be more explicit that it is collecting residential address. Another member stated that it might be better to require data collection of residential address earlier in the process and suggested to place that data element on the Living Donor Feedback form, to which the Workgroup agreed.

The Workgroup considered adding a data element to the Living Donor Feedback form to collect family history of end stage organ disease. The Workgroup agreed that the Living Donor Feedback form should remain short and concise, and that this data would be more appropriately suited on the LDR form.

Another member asked whether the Living Donor Feedback form should include a data element to collect if the living donor lives outside of the United States. A member questioned the necessity of collecting citizenship status data elements. Another member responded that the citizenship status data element helps inform analyses and evidence-based care.

One member brought up whether they should modify the donor gender data field to update it with relevant and appropriate language. Staff assented, stating that efforts were already underway to make changes to the donor gender data field as well as donor race/ethnicity.

### **Upcoming Meeting**

- March 17, 2023
- April 21, 2023

## Attendance

- **Workgroup Members**
  - Angele Lacks
  - Jesse Schold
  - Paul MacLennan
  - Macey Levan
  - Nahel Elias
  - Stevan Gonzalez
  - Vineeta Kumar
- **HRSA Representatives**
  - Adriana Martinez
  - Mesmin Germain
- **SRTR Staff**
  - Krista Lentine
- **UNOS Staff**
  - Brooke Chenault
  - Carol Covington
  - Eric Messick
  - Jennifer Wainright
  - Meghan McDermott
  - Ruthanne Leishman
  - Samantha Weiss
  - Stryker-Ann Vosteen