

**OPTN Living Donor Committee  
Meeting Summary  
May 10, 2023  
Conference Call**

**Nahel Elias, MD, Chair  
Stevan Gonzalez, MD, Vice Chair**

## **Introduction**

The OPTN Living Donor Committee (the Committee) met via Citrix GoToMeeting teleconference on 05/10/2023 to discuss the following agenda items:

1. Project Overview and Meeting Goal
2. Discussion: Living Donor Data Collection

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

### **1. Project Overview and Meeting Goal**

The Committee heard the detailed recap of the previous meeting on April 26, 2023, which included a discussion of what a potential definition for a "living donor candidate" should be. The Committee concluded that a "living donor candidate" is an individual who was seen (virtually or in person) at a transplant center for evaluation. The Committee additionally discussed further defining "evaluation" and requested community input on this topic during public comment.

### **2. Discussion: Living Donor Data Collection**

The Committee provided pre-meeting input of potential data collection options for living donor candidates.

#### Summary of discussion:

The input provided prior to the meeting on potential data collection options:

- Potential data collection for living donor candidates: Only demographic data
  - This would be incomplete data
  - Need clinical data to inform impact of donation, such as change in renal function
  - Demographic data would serve informational purpose for things already largely known, such as the ration of men to women living donors
  - Includes vital data for assessment of barriers to transplantation but misses important medical conditions or possible risk factors for worse outcomes
- Potential data collection for living donor candidates: Only clinical data
  - This would be incomplete data
  - Need demographic data to understand how disparities impact donation
  - Depending on how much clinical data is sought, it could require more resources from transplant programs
  - Includes medical information which can aid in risk assessment, but misses a very important component of social factors in determining barriers to transplantation

- Potential data collection for living donor candidates: Combination of clinical and demographic data (similar to the SRTR Living Donor Collective)
  - Ideal state – best option in terms of providing true insight on living donor health and outcomes
  - Collecting maximum amount of data up front would allow for more nuanced evaluation down the line
  - Lengthiest and most involved – highest burden on transplant programs to complete
  - Need to determine what data points will be collected to ensure added burden on transplant programs is minimized
- Potential data collection for living donor candidates: Minimum amount of demographic and clinical data (similar to the OPTN Living Donor Feedback form)
  - May not be sufficient data in order to know more about living donors and barriers to donation
  - Burden on transplant programs is less than previous option
  - Could be expanded by reviewing what other variables may be essential
- Other data points members felt needed to be taken into consideration
  - Consider adding psychosocial data – during evaluation, information is gathered on mental health, substance use history, potential financial impact on donation, support, etc.
  - Living donors self-report data through a living donor app

The pre-meeting input indicated that most members felt collecting a more robust combination of both demographic and clinical data, similar to what the Living Donor Collective collects, would provide the most useful information on living donor candidates. Members discussed which process would best streamline and optimize the data collection process, highlighting that input from key stakeholders would be essential during the public comment period. The Chair suggested collecting a more limited set of data on living donor candidates who do not proceed to donation and a more expansive set of data on living donor candidates who do proceed with donation. The Vice-Chair noted that the purpose of this proposed concept is to streamline redundancy in data collection processes.

The Vice Chair proposed that the Committee compare pre-donation data collected by the OPTN and SRTR. The Vice Chair stated that comparing this data will help understand where redundancy may occur which may help receive buy-in from the community as well as inform important feedback. An SRTR representative informed the Committee that the Living Donor Collective's living donor candidate registration was modelled on the Living Donor Registration (LDR) form.

Members discussed the best time to collect each data element. Certain elements, such as date of birth, only need to be collected once, while others require multiple collections. A member reiterated their concern that the burden of data collection will fall primarily on the transplant programs, so it is crucial to determine the impact and inform the transplant program accordingly. This member emphasized that the rationale for increasing the amount of data collected should be clearly explained in the concept paper. The member suggested the Committee estimate the percent increase in data collection for living donor candidates compared to living donors in order to inform decision making and community feedback. The member noted that their transplant program allows three potential living donors per transplant candidate to be evaluated which means the data collection may be a significant increase.

A member noted that donation decision data may not need to be collected indefinitely. The member explained that barriers to living donation may become evident after a couple years of collecting donation decision in which case it could then no longer be required. The member stated that it depends on the goal of the data collection to determine how long the data collection is necessary.

Members discussed other elements that might be necessary to consider for data collection, such as the psychosocial and socioeconomic, and whether these elements should be considered mandatory or voluntary. The Committee considered the seeking feedback from the community on the priority of the data elements that are important to collect. Members also agreed that public feedback and comments are deemed critical to ensure that priorities align with the community's perspectives.

Another member suggested to collect data on whether or not a living donor regrets their decision to donate. The member noted that future living donors are often informed by prior living donor experiences.

The Committee agreed that the goal of living donor candidate data collection is to improve analysis on long-term living donor outcomes and barriers and access to living donation.

Next steps:

The Committee will continue to discuss which data may be necessary to collect on living donor candidates and which data may be voluntary.

**Upcoming Meeting**

- May 17, 2023 (teleconference)
- May 24, 2023 (teleconference)
- June 14, 2023 (teleconference)

## Attendance

- **Committee Members**
  - Aneesha Shetty
  - Ashtar Chami
  - Dylan Adamson
  - Henkie Tan
  - Katey Hellickson
  - Mary Beth Stephens
  - Nancy Marlin
  - Nahel Elias
  - Alexandra Shingina
  - Stevan Gonzalez
  - Tyler Baldes
  - Vineeta Kumar
  - Laura Butler
- **HRSA Representatives**
  - Arjun Naik
  - Jim Bowman
  - Mesmin Germain
- **SRTR Staff**
  - Krista Lentine
  - Katie Siegert
- **UNOS Staff**
  - Carol Covington
  - Jennifer Wainright
  - Kim Uccellini
  - Laura Schmitt
  - Meghan McDermott
  - Samantha Weiss
  - Stryker-Ann Vosteen