

**OPTN Living Donor Committee  
Living Donor Data Collection Workgroup  
Meeting Summary  
April 21, 2023  
Conference Call**

## **Introduction**

The Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 04/21/2023 to discuss the following agenda items:

1. New Living Donor Committee Project Background: Living donor candidate and donation decision data collection project
2. Discussion: Living donor candidate definition and living donor candidate data collection options

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

### **1. New Living Donor Committee Project Background: Living donor candidate and donation decision data collection project**

The Workgroup received an update on the Living Donor Committee's new project regarding living donor candidate and donation decision data collection.

#### Summary of discussion:

There were no comments or questions.

### **2. Discussion: Living donor candidate definition and living donor candidate data collection options**

The Workgroup discussed potential ways to define a living donor candidate, as well as possible data collection options for living donor candidates.

#### Summary of discussion:

Input provided prior to the meeting on potential definitions for a living donor candidate:

- Potential definition: Someone who has contacted a living donor program with interest in living donation
  - This is very early but may be too wide of a net
  - May include individuals who are just looking for more information, but not truly initiating the living donor process
  - This definition should be considered a potential living donor candidate
  - This definition may capture a larger number of people than intended
  - Difficult to collect meaningful data from those who remove themselves from living donor candidacy before phone screening
  - It is not clear how valid basic demographics would be collected without even a phone screen. Patient contact and survey would be burdensome
- Potential definition: Someone who underwent a phone screening with a transplant program
  - This is very early in the process, but net remains wide
  - Would be interesting from a data-gathering perspective, but may increase burden to programs
  - This definition should be considered a *potential living donor candidate*

- Transplant centers have varied processes for contacting and screening living donor candidates, so this definition may cause confusion if a center starts the evaluation process with something than a phone screening.
- Some information of value, e.g., self-reported demographic, family history, occupational, and clinical factors that potentially play a role in access/barriers to donation might be collected.
- A large amount of self-reported data would be collected. As candidates move forward in the evaluation process, the data quality would improve since there'd be less dependence on self-report.
- Potential definition: Someone who was seen at the transplant program for evaluation
  - This may be ideal - truly identifies a committed candidate
  - May not increase burden on programs as much, as they are already engaging with candidates and obtaining data at this stage
  - This definition should be considered a *potential living donor candidate*
  - This definition is accurate.
  - Validity and quality of the data would be high but would be unable to collect data regarding pre-evaluation barriers.
- Potential definition: Someone who underwent an evaluation at the transplant program and is approved to be a living donor
  - This is too late - if we only obtain data on approved candidates, we miss the opportunity to look at barriers to living donation
  - Agree that this is how *living donor candidate* should be defined
  - This definition may exclude people who are able to be living donors, but their intended recipient is no longer a transplant candidate.
- Should be the highest quality of data but it's not informative re the process leading to approval. The two definitions that came out as preferred were that a living donor candidate is an individual who was seen at a transplant program for evaluation, or a living donor candidate is an individual who underwent evaluation at the transplant program and was approved to be a living donor.

Members debated all of the definitions, specifically focusing on when in the process gathering this data is going to play an important role. The Workgroup decided against the definition of someone who has contacted a living donor program with an interest as it is a very broad definition. Members recognized the benefit that gathering data as early as possible can have, but expressed concern for the increased burden this would place on transplant coordinators and transplant programs in general. Members also discussed the fact that different transplant programs use different screening tools and algorithms to determine who should be moved forward in the living donor candidate process. A representative of the SRTR added that the Living Donor Collective defines a living donor candidate as someone who was seen at the transplant program for evaluation. The SRTR representative added this definition helps with ensuring completeness of the data and the ability for transplant programs to complete those forms without too much burden.

Members reached a consensus that though gathering data earlier on in the process would provide more data on barriers to living donation, the increased burden it would have on transplant programs and coordinators would be excessive. A member of the Transplant Coordinators Committee echoed this sentiment, also highlighting the way the process is currently, living donor candidates are not registered in the OPTN system until they are about to become living donors, therefore just before surgery. The SRTR representative opined that this is because the current system is not set up to collect data on living donor candidates, only living donors, hence the need for this project.

Input provided prior to the meeting on potential data collection for living donor candidates:

- Potential living donor candidate data collection: Only demographic data
  - Demographic information is important, but more than that is needed.
  - Only collecting demographic data means then there would not be access to clinical data
  - Without clinical data, we will not be able to use the data to understand outcomes of living donation. Additionally, unless race and ethnicity are self-reported, the data may not be accurate. We should collect contact information so we can improve our methods for contacting prior living donors.
- Potential living donor candidate data collection: Only clinical data
  - Clinical information is important, but more than that is needed to get a full picture of the living donor
  - Only collecting clinical data means then there would not be access to demographic data
  - We should collect social and demographic data so we can understand the impact of social determinants of health on living donor outcomes and develop interventions to improve care.
- Potential living donor candidate data collection: Combination of demographic and clinical data (same as Living Donor Collective)
  - A combination of clinical and demographic data allows for a more granular look at donor information.
  - With this living donor trends and similarities can be followed to help shed light on where living donor education needs lie.
  - This would be best - would align with SRTR Living Donor Collective and obtain different types of data
  - We should collect both demographic and clinical data, but expand demographic data to include questions regarding ancestry so we can better study genetic variants such as APOL1.
- Potential living donor candidate data collection: Minimum amount of demographic and clinical data
  - Based on the SRTR Living Donor Collective's Data, I think fewer data elements would be helpful. This is an exhaustive list for those responsible for reporting the data to fill out.
  - May not have sufficient data
  - I disagree, I think we should use the literature to identify what other data elements are most needed to conduct research to improve care for living donors.
- The two types of data collection that were preferred by the Workgroup were to collect a combination of demographic and clinical data similar to that of the SRTR Living Donor Collective, or to collect the minimum amount of demographic and clinical data.

The Workgroup briefly discussed the potential data collection for living donor candidates. After some debate, members agreed that the two preferences for data collection should be debated by the Living Donor Committee. Members did, however, express that collecting more information on demographic and clinical data would be the better option.

A member suggested that living donor candidates who are approved could have different data collected than living donor candidates who do not proceed to donation. The member explained that there may be more data elements that are necessary to collect on approved living donor candidates than there would be for a living donor candidate that was denied. The Workgroup was interested in seeking feedback from living donor transplant coordinators in order to understand opportunities to streamline data collection processes.

## **Upcoming Meeting**

- June 16, 2023 (teleconference)

## Attendance

- **Workgroup Members**
  - Angele Lacks
  - Jesse Schold
  - Paul MacLennan
  - Nahel Elias
  - Stevan Gonzalez
- **HRSA Representatives**
  - Mesmin Germain
  - Arjun Naik
- **SRTR Staff**
  - Katie Siegert
  - Krista Lentine
- **UNOS Staff**
  - Jennifer Wainright
  - Laura Schmitt
  - Meghan McDermott
  - Samantha Weiss
  - Sara Langham
  - Stryker-Ann Vosteen
  - Suhuan Wang
- **Other Attendees**
  - Carolyn Sidoti