

**OPTN Living Donor Committee  
Living Donor Data Collection Workgroup  
Meeting Summary  
December 20, 2021  
Conference Call**

## **Introduction**

The Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 12/20/2021 to discuss the following agenda items:

1. Summary of Living Donor Committee's Feedback
2. Overview and Discussion of Draft Project Form

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

### **1. Summary of Living Donor Committee's Feedback**

The Living Donor Committee (Committee) discussed long-term data collection for living donors during their December 8, 2021 meeting. The Workgroup was informed of their feedback.

#### Summary of discussion:

The Committee provided reasons for why collecting long-term data on living donors is important, as well as concerns for expanding long-term data collection. The Committee also provided suggestions for types of donor data collection. The Committee suggested expanding follow-up to five or ten years may be an initial step. The Vice Chair emphasized that the living donor's perspective on what data is valuable is important if the Workgroup develops any data collection changes.

### **2. Overview and Discussion of Draft Project Form**

The Workgroup discussed the specifics of a potential project in order to create a project form.

#### Summary of discussion:

The Workgroup discussed the purpose of the potential project is to collect data on candidates for living donations and living donors. Collecting these data will aid in:

- Enabling living donors' informed consent, including outcomes beyond two years
- Better understanding of barriers to living donation and how to overcome these barriers
- Better understanding lifetime risks to donors attributable to donation and how these risks might be prevented or mitigated

The Workgroup recognized that this potential project may affect OPTN policy, such as OPTN Policy 18.5: Living Donor Data Submission Requirements. Additionally, the potential project may affect data collection through the Living Donor Feedback, Living Donor Registration (LDR), and Living Donor Follow-up (LDF) forms.

The Workgroup found no impact to either organ procurement organizations or histocompatibility labs. Transplant programs may be impacted by changes to data submission, however the impact is yet to be determined.

The Workgroup will continue to collaborate with the OPTN Data Advisory Committee (DAC). The Workgroup identified additional stakeholder groups:

- Living donor candidates and living donors
- American Association of Kidney Patients
- National Kidney Foundation
- Transplant Professional Societies
- American Association for the Study of Liver Diseases
- American Society of Transplantation
- American Society of Transplant Surgeons
- American Society of Nephrology

The Workgroup will address the following questions pertinent to living donor data collection and they develop their project.

- What long-term follow-up data should be collected, and who should collect it?
- Should some or all required OPTN follow-up beyond six months be eliminated, reducing the burden of data collection for programs and allowing other data to be collected?
- Can candidate registration data elements and definitions that are similar for the Living Donor Collection and the OPTN data be harmonized so that when these data elements are collected by both the Living Donor Collective and the OPTN they are the same?
- Do data elements and definitions need to be changed, particularly for the Living Donor Collective list of reasons for not donating?

The Workgroup discussed that the potential project may align with the strategic goal of promoting living donor and transplant recipient safety.

A member suggested that the Living Donor Collective should collect the majority of living donor data. The member explained that the most informative data will be yielded in the long-term. The member stated that the OPTN should collect living donor data related to safety, such as perioperative deaths. The member added that having the OPTN focus on the perioperative period up to one year will be important for the MPSC to monitor living donor safety.

Another member stated that the Workgroup needs to discuss how OPTN policy on living donor data collection can dovetail with the Living Donor Collective. The member explained that the Workgroup will need to identify the aims of each entity and ensure alignment of the short and long term goals, then the Workgroup will need to decide how to revise OPTN policy appropriately. The member stated that once the Living Donor Collective is established, the OPTN policy could be modified to collect living donor data that is short-term and center specific. The member stated that this may require an obligation from transplant programs to enroll living donor candidates in the Living Donor Collective.

A member stated that the Workgroup will need to consider how the Living Donor Collective can relay information and data back to the living donor transplant programs. SRTR responded that transplant programs that are enrolled in the Living Donor Collective are able to review their data, as well as compare their data to other Living Donor Collective participants. SRTR staff added that the Living Donor Collective is also available to the public.

The Workgroup was informed of the OMB process to understand the implementation timelines if future changes to OPTN data collection forms should occur. A member suggested that the Workgroup will need to understand the process of modifying data collection captured within the Living Donor Collective. The Workgroup will continue discussions.

### **Upcoming Meeting**

- TBD

## Attendance

- **Workgroup Members**
  - Angie Nishio Lucar
  - Nahel Elias
  - Heather Hunt
  - James Trotter
  - Randy Schaffer
  - Sumit Mohan
- **HRSA Representatives**
  - Chris McLaughlin
  - Shannon Dunne
  - Jim Bowman
  - Marilyn Levi
  - Raelene Skerda
- **SRTR Staff**
  - Ajay Israni
  - Bert Kasiske
  - Christian Folken
  - Jon Snyder
  - Krista Lentine
- **UNOS Staff**
  - Anne McPherson
  - Brooke Chenault
  - Jennifer Wainright
  - Kristine Althaus
  - Lauren Motley
  - Lindsay Larkin
  - Meghan McDermott
  - Matt Prentice
  - Nadine Hoffman