

**OPTN Living Donor Committee  
Living Donor Data Collection Workgroup  
Meeting Summary  
February 16, 2022  
Conference Call**

## **Introduction**

The Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 02/16/2022 to discuss the following agenda items:

1. Update on Resource Budget Discussions
2. Update on Project Plan

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

### **1. Update on Resource Budget Discussions**

The Workgroup was updated that the OPTN Policy Oversight Committee (POC) has been analyzing and discussing the current resource budget. The POC will continue to evaluate the resource budget and determine long-term plans for project prioritization.

A member asked how the Workgroup can ensure prioritization as the POC continues their evaluation of resources and projects. Staff responded that the POC is informed of this project and its potential resource impact. Staff added that the resource impact will depend on the size of the project, and whether its scope is addressed in a phased approach. A member of the POC stated that they are also discussing the ability to ask for an increase in resources in order to help with project prioritization.

### **2. Update on Project Plan**

The Workgroup discussed the project plan.

#### Summary of discussion:

To date, the Workgroup and the OPTN Living Donor Committee have thoroughly discussed the reasons for living donor data collection, as well as challenges. SRTR staff drafted an initial project plan and questions. In consideration of the policy development process, it was recommended that a phased approach will aid the project in having a focused scope. Additionally, the OPTN Data Advisory Committee (DAC) has been discussing how to approach a holistic review of OPTN data collection.

The Workgroup reviewed the following previously identified reasons for why living donor data collection is important:

- To better understand barriers to living donation, so that these barriers may be safely overcome
- To promote ongoing communication between transplant program and donors
- To enable living donors' informed consent, including outcomes beyond two years
- To help potential living donors communicate risk with their families
- To better understand lifetime risks to living donors attributable to donation, and how these risks might be prevented or mitigated
- To better monitor overall and individual transplant program trends in performance and patient safety

- To inform HRSA's annual report to Congress on living donation

A member suggested mapping out the full project scope and phased approach in order to view a timeline of the project. Staff stated that the first step will require consensus on what data is necessary for living donor follow-up. Staff added that an option for the project is to submit a recommendation to the OPTN Board of Directors in order to receive input and support on a proposed plan.

A member of DAC stated that this project aligns well with the DAC's current efforts to holistically review OPTN data. The member added that it is important to consider the uses of the data, including safety, quality, and research. Another member suggested that the DAC may provide an overview of their holistic review of OPTN data collection to the Living Donor Collection.

A member suggested to include additional living donors in order to have a broader view of what is important to a variety of living donors. The member added that social workers may offer an important perspective too.

Another member suggested that the project could be divided to first address the data collection that is necessary in the short-term, and then address data that is more necessary for long-term outcomes.

#### **Upcoming Meeting**

- TBD

## Attendance

- **Workgroup Members**
  - Angie Nishio Lucar
  - Caitlyn Nystedt
  - Heather Hunt
  - James Trotter
  - Macey Levan
  - Nahel Elias
  - Rachel Patzer
  - Randy Schaffer
  - Sumit Mohan
  - Vineeta Kumar
- **HRSA Representatives**
  - Adriana Martinez
  - Jim Bowman
  - Marilyn Levi
  - Raelene Skerda
  - Vanessa Arriola
- **SRTR Staff**
  - Bert Kasiske
  - Christian Folken
  - Jon Snyder
  - Krista Lentine
- **UNOS Staff**
  - Anne McPherson
  - Cole Fox
  - James Alcorn
  - Kaitlin Swanner
  - Kim Uccellini
  - Lauren Mauk
  - Lauren Motley
  - Leah Slife
  - Lindsay Larkin
  - Meghan McDermott
  - Rebecca Goff
  - Samantha Noreen
  - Samantha Weiss