

**OPTN Living Donor Committee
Living Donor Data Collection Workgroup
Meeting Summary
July 30, 2021
Conference Call**

Introduction

The Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 07/30/2021 to discuss the following agenda items:

1. Workgroup Purpose Discussion
2. Brief Overview of Living Donor and Data Advisory Committee Projects
3. SRTR Living Donor Collective Overview
4. Path Forward

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

1. Workgroup Purpose Discussion

The Workgroup was formed to discuss the future of living donor data collection for the organ transplantation system.

Summary of discussion:

The OPTN has collected living donor data for over ten years through the Living Donor Registration (LDR) form, as well as the Living Donor Follow-up (LDF) form, which is submitted 6-, 12-, and 24-months post-transplant.

HRSA is required to annually report on long term living donor outcomes to United States Congress. However, the data collected on the LDF forms does not allow for sufficient long term outcome data reports.

In recent years, the SRTR was contracted to pilot a project regarding collection of long term health outcomes of living donors. This project, the Living Donor Collective, has now become a permanent contractual project for the SRTR.

The Workgroup will discuss how to ensure the Living Donor Collective is a robust source of information for analysis and research, as well as potential changes to OPTN living donor data collection, given the Living Donor Collective's attempt to be a long term living donor registry. The Workgroup will discuss data which should be collected through the Living Donor Collective, and data which should be collected through the OPTN, and provide such guidance.

2. Brief Overview of Living Donor and Data Advisory Committee Projects

The Workgroup reviewed projects that the Living Donor Committee (LDC) and Data Advisory Committee (DAC) are currently working on.

Summary of discussion:

LDC projects:

- Active project: Evaluate Living Donor Exclusion Criteria

- To be implemented: Data Collection on Living Vascularized Composite Allograft (VCA) Donors

DAC projects:

- Active project: Defining Late Turndowns
- To be implemented: Update to Refusal Codes
- To be implemented: Modify Data Submission Policies – Data Lock
- Ongoing project: Data definition clarification review
- Ongoing project: Collaboration and review of data collection proposals

3. SRTR Living Donor Collective Overview

The Workgroup was given an overview of the Living Donor Collective.

Summary of discussion:

During the pilot phase of the Living Donor Collective, there were 10 living donor kidney programs and 6 living donor liver programs that were involved. The pilot tested uploading batches of data straight from electronic platforms, and they continue to implement these processes while continually improving on efficient technological processes.

The Living Donor Collective allows participating programs to review their own data, as well as compare to other participating programs' data, while protecting PHI information and identities of participating programs. Additionally, the data accessible for researchers through applications.

As the Living Donor Collective has become a permanent contractual project, the SRTR's long term goal is to engage participation from every living donor program in the United States. Unique to the Living Donor Collective, is their data collection surrounding candidate reason for not donating.

SRTR staff emphasized the Workgroup can assist in improving the efficiency of data collection by addressing which entities should collect specific data. The Workgroup can analyze what the data needs are related to living donation, and which system should address those data needs.

4. Path Forward

The Workgroup will need to consider a timeline for OPTN Policy Oversight Committee & Executive Committee project approval. The Workgroup expressed interest in engaging with stakeholder organizations and patients early in the process.

HRSA reminded the Workgroup of the National Institute of Health's (NIH) APOL1 Long-term Kidney Transplantation Outcomes Network (APOLLO) study for additional living donor data which could be tied in.

The Workgroup leadership will work on identifying goals and objectives for the Workgroup. The Workgroup will review the SRTR's assessment of the LDR and LDF forms.

The Workgroup will continue discussions surrounding living donor data collection through the Living Donor Collective and OPTN data collection forms.

Upcoming Meeting

- TBD

Attendance

- **Workgroup Members**
 - Ajay Israni
 - Aneesha Shetty
 - Brad Kornfeld
 - Heather Hunt
 - James Trotter
 - Macey Levan
 - Rachel Patzer
 - Randy Schaffer
 - Vineeta Kumar
- **HRSA Representatives**
 - Arjun Naik
 - Chris McLaughlin
 - Shannon Dunne
 - Marilyn Levi
 - Raelene Skerda
 - Vanessa Arriola
- **SRTR Staff**
 - Bert Kasiske
 - Chris Folken
 - Jon Snyder
 - Krista Lentine
- **UNOS Staff**
 - Kaitlin Swanner
 - Lindsay Larkin
 - Matt Prentice
 - Meghan McDermott
 - Robert Hunter
 - Sarah Konigsburg
 - Susan Tlusty