

**OPTN Living Donor Committee
Living Donor Data Collection Workgroup
Meeting Summary
October 8, 2021
Conference Call**

Introduction

The Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 10/08/2021 to discuss the following agenda items:

1. Discussion on Workgroup Goals and Vision
2. Path Forward

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

1. Discussion on Workgroup Goals and Vision

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

Summary of discussion:

HRSA staff explained that the current mechanisms to collect living donor outcome data is through the OPTN 2 year follow-up period and the SRTR Living Donor Collective initiative. HRSA staff added that the Workgroup is welcome to explore other mechanisms. The Workgroup is expected to define a vision for the future of living donor data collection by discussing the kinds of data collection that are needed for living donors and the appropriate mechanisms to collect said data.

A member asked when that last time the OPTN requested feedback from prior living donors to understand what information is important to them. Staff responded that when the OPTN living donor data collection forms were created, they were submitted for Public Comment. During this period, it is likely that patient stakeholder groups would have provided feedback. However, prior living donors have not been engaged for feedback on living donor data collection since that time. HRSA staff added that there was an American Society of Transplantation (AST) conference several years ago that had recommendations regarding living donor follow-up which included feedback from patients.¹ The member suggested that a component of this project should be to target patients to obtain feedback on what is beneficial information and data for living donors. SRTR staff agreed and suggested to broaden this idea to include living donor candidates who do not go on to donate. Another member suggested that social media groups for living donors may be an avenue to gather this feedback.

UNOS staff stated that the Living Donor Committee initially created the Living Donor Follow-up (LDF) forms to ensure that transplant programs were interacting with prior living donors at certain time

¹ Living Kidney Donor Follow-Up Conference Writing Group, Leichtman, A., et al. (2011). Living kidney donor follow-up: state-of-the-art and future directions, conference summary and recommendations. *American journal of transplantation: official journal of the American Society of Transplantation and the American Society of Transplant Surgeons*, 11(12), 2561–2568. <https://doi.org/10.1111/j.1600-6143.2011.03816.x>

periods, post-donation. The Workgroup acknowledged that living donor outcome data is needed for patient education and care, as well as for HRSA's annual report on living donor outcomes to Congress.

Another member recognized the data burden placed on programs and suggested that the Workgroup first consider what data is needed for living donation, and then find the right pathway for that collection. SRTR staff suggested the idea of a living donor advocacy group, run by prior living donors, in order to collect data. SRTR staff explained that there are patient advocacy groups for rare diseases that have been very successful in collecting their own data. HRSA staff asked if the Living Donor Collective would back a patient advocacy group such as this. SRTR staff stated that regular and early contact is important, and stated there are different approaches to maintaining contact with prior living donors. UNOS staff added that it will be necessary to consider how to maintain contact with prior living donors who are high risk and not easily engaged via social media and technology.

The Workgroup discussed the ability for reporting patient safety events and trends. HRSA acknowledged that developing a feedback loop may be needed, and that they will further discuss this possibility.

2. Path Forward

SRTR staff emphasized that an important aspect of this project is harmonizing baseline collection, through OPTN data collection forms and the Living Donor Collective, and making an efficient process for living donor data entry. SRTR staff added that harmonizing the baseline collection of living donor data entry is important for the Living Donor Collective to increase broad transplant program participation. UNOS staff asked if the vision for the Workgroup should be drafted with consideration for how living donor data collection should be in ten years or how living donor data collection could be within the next year anchored by the SRTR and OPTN contracts and the current data collection within multiple systems. HRSA staff responded that it would be useful for the Workgroup to consider both of those options, but improvement in the short-term is welcome.

Next Steps:

The Workgroup will receive a document outlining a framework to aid in the development of a vision. The Workgroup will continue discussions on identifying a vision and goals for the future of living donor data collection.

Upcoming Meeting

- TBD

Attendance

- **Workgroup Members**
 - Aneesha Shetty
 - Angie Nishio Lucar
 - Heather Hunt
 - Sumit Mohan
- **HRSA Representatives**
 - Chris McLaughlin
 - Shannon Dunne
 - Jim Bowman
 - Raelene Skerda
 - Vanessa Arriola
- **SRTR Staff**
 - Bert Kasiske
 - Caitlyn Nystedt
 - Christian Folken
 - Jon Snyder
 - Krista Lentine
- **UNOS Staff**
 - Anne McPherson
 - James Alcorn
 - Janis Rosenburg
 - Jennifer Wainright
 - Kim Uccellini
 - Kristine Althuas
 - Lauren Motley
 - Leah Slife
 - Lindsay Larkin
 - Meghan McDermott
 - Roger Brown
 - Samantha Noreen