

OPTN Living Donor Committee

Meeting Summary

May 24, 2023

Conference Call

Nahel Elias, MD, Chair

Stevan Gonzalez, MD, Vice Chair

Introduction

The OPTN Living Donor Committee (the Committee) met via Citrix GoToMeeting teleconference on 05/24/2023 to discuss the following agenda items:

1. Project Progress
2. Discussion: Living Donor Follow-up

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

1. Project Progress

The Committee reviewed decisions made at prior meetings on 4/26, 5/10, and 5/17.

Data summary:

Committee Meeting 4/26/2023

- The Committee reached a consensus on how to define a living donor candidate, as "someone who is seen virtually or physically for evaluation at a transplant program".
- The Committee also discussed what "evaluation" might mean for different programs and concluded that this would be a question to ask the community during Public Comment.

Committee Meeting 5/10/2023

- The Committee discussed in detail what the living donor and living donor candidate data collection needs are and when it should be collected in the process.

Committee Meeting 5/17/2023

- The Committee discussed data elements collected by both the OPTN and the SRTR during the living donation process, working to determine which data elements are most critical to collect on living donor candidates.
- The Committee decided that the concept paper should include estimates on the amount of data elements deemed necessary and would provide details on what those elements specifically entail.

Summary of discussion:

The Committee heard from both the Chair and the Vice-Chair about recent presentations to the Transplant Administrators (TAC) and Transplant Coordinators Committees (TCC), citing concerns both committees brought up about the potential increase in living donor candidate volume and the time it requires to do living donor follow-up.

Members briefly discussed the decisions made at the prior meetings, agreeing with concerns of both TAC and TCC that both program volume and practices can vary greatly, heightening the need for consistent expectations.

2. Discussion: Living Donor Follow-Up

The Committee continued their discussion on what would constitute adequate living donor follow-up and how to ensure it results in holistic data collection. Additionally, they discussed what types of questions should be asked in the concept paper to get a sense of what the community feels is necessary for living donor follow-up and what transplant programs know to be feasible.

Summary of discussion:

Decision: The Committee decided that the feedback from the community on the concept paper would be integral to helping clarify the questions remaining regarding how to conduct adequate living donor follow-up.

The Committee discussed the existing OPTN requirements for living donor follow-up which includes contacting the living donor at the 6-, 12-, and 24-month mark post-donation and how shifting that requirement to the SRTR Living Donor Collective might look moving forward. Committee members agreed that there are many questions they alone cannot answer without input from the community as they pertain to what data elements are important to collect as well as when these elements will carry the most weight and be important for understanding the long-term implications of being a living donor.

A question regarding the difference in OPTN contract requirements vs SRTR contract requirements brought to light the fact that any changes the OPTN makes to data collection efforts are required to go through a public comment cycle so that the community can weigh in on any changes. Meanwhile, the SRTR does not have the same requirement, and can amend living donor follow-up data collection efforts as they see fit. The Committee felt that it would be an important question to ask whether the community is comfortable with this change. Additionally, a representative of the SRTR brought up the concern that the SRTR Living Donor Collective is currently voluntary. The Chair mused that should this collaboration between the OPTN and the SRTR move forward as outlined in the concept paper, then would participation in the Living Donor Collective become mandatory.

An SRTR representative stated that the Living Donor Collective has focused on registering living donor candidates and as such the long-term follow-up is not as developed. The SRTR representative emphasized the importance of collaboration to develop the long-term follow-up through the Living Donor Collective.

A member suggested to ask the community feedback on whether removing the 1- and 2-year OPTN follow-up requirements would help support the shift in data collection upstream.

The Committee discussed whether it would be possible to have these forms integrated into the electronic medical records (EMR), however, they acknowledged that this would be a better question for IT staff than the transplant community. Members agreed that this would be beneficial to consider in the concept paper, another member clarified that certain data elements are often already included in the EMR's and so the responsibility of data collection could be lessened on transplant programs.

Next steps:

The Committee discussed the next steps for the concept paper, and the questions that should be included in the paper for the community to answer. The OPTN Contractor staff confirmed that the

Committee would have a finalized draft to review before the next meeting on June 14th, and that they would go over that draft and make any adjustments or edits as needed.

Upcoming Meeting

- June 14, 2023 (teleconference)

Attendance

- **Committee Members**
 - Aneesha Shetty
 - Astar Chami
 - Dylan Adamson
 - Henkie Tan
 - Katey Hellickson
 - Laura Butler
 - Nahel Elias
 - Nancy Marlin
 - Mark Payson
 - Stevan Gonzalez
 - Tyler Baldes
 - Vineeta Kumar
- **HRSA Representatives**
 - Jim Bowman
 - Mesmin Germain
 - Marilyn Levi
- **SRTR Staff**
 - Krista Lentine
 - Caitlyn Nystedt
 - Katie Siegert
- **UNOS Staff**
 - Carol Covington
 - Jennifer Wainright
 - Kim Uccellini
 - Laura Schmitt
 - Meghan McDermott
 - Sam Weiss
 - Sara Langham
 - Stryker-Ann Vosteen
- **Other Attendees**
 - Chris Woody