

OPTN Living Donor Committee

Meeting Summary

May 17, 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 05/17/2023 to discuss the following agenda items:

1. Project Progress
2. Discussion: Living Donor Candidate Data Collection

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

1. Project Progress

The Committee reviewed the discussions and decisions that occurred during previous Committee meetings. The Committee discussed whether they wanted to provide the community updates on their project during the upcoming public comment cycle and receive feedback or wait in order to refine the project further.

Summary of discussion:

The Vice Chair reminded that Committee that the benefit of developing a concept paper for this project is that it allows the Committee to overview broad concepts in order to receive feedback from the community. The Vice Chair stated that the granular details are not necessary to include in the concept paper, and those decisions are better reserved for a final proposal.

The Chair agreed and added it is important to receive feedback from the community on these concepts sooner than later.

Next steps:

The Committee will continue developing a concept paper to submit for the upcoming Summer 2023 public comment period.

2. Discussion: Living Donor Candidate Data Collection

The Committee provided pre-meeting input on pre-donation data elements that are necessary to collect for living donor candidates.

Summary of discussion:

Prior to the meeting members were provided a cross-walk of pre-donation data elements that are collected by the OPTN and the SRTR Living Donor Collective. The input provided prior to the meeting on potential data collection for living donor candidates included:

- Consensus on five data elements that are necessary to collect on living donor candidates
 - Date of birth, organ type, name, sex, and ethnicity/race

- The remaining ~60 pre-donation data elements did not have consensus

A member noted that data elements related to contact information such as address and phone may be important to determine how best to follow-up with living donor candidates and living donors. The Chair noted that zip code is also beneficial for analyzing social determinants of health. An SRTR representative noted that if the OPTN collects living donor candidate data, then the Living Donor Collective would perform long-term follow-up. Therefore, collecting detailed contact information will be beneficial for the Living Donor Collective when performing the long-term follow-up. The Vice Chair noted that it would be expected for living donor candidates to give this type of information when they are being evaluated by a transplant program. The SRTR representative stated that there has not been difficulty collecting contact information in the Living Donor Collective experience.

The Committee agreed it is necessary to collect contact information on living donor candidates.

Another member asked whether marital status is an important data element. Staff stated that the Committee's previous review of this data element resulted in the recommendation to remove it, and instead collect data related to social support. A member suggested to collect *does the individual have social support for the recovery period?*

A member advocated that collecting information regarding whether the donation will be a financial hardship is important. The member stated that collecting this data may promote more financial support for living donors. Another member agreed.

A member reminded the Committee of feedback from the OPTN Data Advisory Committee (DAC). The member stated that the DAC suggested to align data collection with that of transplant candidates and recipients for consistency unless there were specific data necessary to living donors.

Another member asked whether functional status or physical capacity are necessary. The Chair stated that it would not be expected for a living donor to have any function or physical limitations. The Committee agreed that collecting functional status or physical capacity is not necessary for living donor candidates.

The Vice Chair stated that the Committee should consider what data is necessary to collect for living donor candidates knowing that there will be additional data collected on living donors. The Vice Chair stated some data may not be necessary to collect during an early time point in the evaluation process, but some data may be important for the longitudinal follow-up of living donor.

A member stated that one of the goals of living donor candidate data collection is to be able to analyze barriers to living donation. The member stated that education level is very important. The member stated that literature related to social determinants of health include education level as a predictor of important outcomes.

A member asked whether collecting *working for income* is necessary for living donor candidates. The Chair noted that this data element is collected on transplant candidates and recipients as well.

The Vice Chair suggested the concept paper include an appendix for the community to reference the pre-donation data elements that are currently being collected by the OPTN and the SRTR Living Donor Collective.

The Chair noted that there may be literature that observes the influence of tobacco on risk of kidney disease. The Chair stated this may be a reason that it is necessary to collect data related to living donor candidates' tobacco usage. A member concurred and stated there is data to suggest that long-term tobacco use increases risk of chronic kidney disease. The Committee agreed that tobacco use is necessary to collect for living donor candidates. A member noted that in order to perform granular analyses on the impact of tobacco use, the data should collect more than yes/no response options.

Another member noted that history of cancer, diabetes, and hypertension are all necessary data to collect on living donor candidates in order to understand long-term outcomes.

A member stated that if data is collected on drug use, it may be important to expand the data collection beyond marijuana use. Another member suggested adding a data element related to history of substance use disorder. The Chair wondered if transplant programs would consider individuals with a substance use disorder for living donation. The member agreed that it may be so few living donor candidates, that it may not be necessary to collect in an effort to minimize data collection. The Vice Chair stated that screening processes may selectively eliminate individuals with substance abuse disorders prior to being seen at a transplant program for evaluation, therefore it may not be necessary to include in this data set for living donor candidates. The member stated that, although it is not common, their transplant program does not automatically rule an individual out due to prior substance use disorder, that it depends on the period of sobriety. The member stated this is only applicable to prior substance use disorders, not current substance use disorders as that is an absolute contraindication.

A member stated that the Committee could ask the community for feedback on whether substance use is a necessary point of data collection for living donor candidates. The member added that collecting information related to mental health would be more important.

The Vice Chair asked whether it is important to collect data on the lipid panel as it relates to hypertension for living donor candidates. The Chair stated that this data collection may be wanted but it might not be necessary. The Vice Chair stated it may be beneficial to collect *does the living donor candidate have diabetes* with binary yes/no response options. The Vice Chair explained that is a way to streamline data collection. The Vice Chair stated it is important to consider which data is more valuable.

Another member agreed that hypertension and diabetes are two important points of information that need to be collected in order to understand long-term outcomes of living donation. A member suggested that the community could provide input on the most efficient and meaningful way to collect this data.

Next steps:

The Committee will continue to discuss concepts for living donor data collection in order to develop a paper for community feedback.

Upcoming Meeting

- May 24, 2023 (teleconference)
- June 14, 2023 (teleconference)

Attendance

- **Committee Members**
 - Aneesha Shetty
 - Ashtar Chami
 - Camille Rockett
 - Henkie Tan
 - Hoylan Fernandez
 - Katey Hellickson
 - Laura Butler
 - Nancy Marlin
 - Nahel Elias
 - Stevan Gonzalez
 - Tyler Baldes
 - Vineeta Kumar
- **HRSA Representatives**
 - Jim Bowman
 - Mesmin Germain
- **SRTR Staff**
 - Caitlyn Nystedt
 - Krista Lentine
 - Katie Siegert
- **UNOS Staff**
 - Carol Covington
 - Kim Uccellini
 - Laura Schmitt
 - Meghan McDermott
 - Samantha Weiss
 - Stryker-Ann Vosteen