

## **OPTN Living Donor Committee**

### **Meeting Summary**

**June 14, 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 06/14/2023 to discuss the following agenda items:

1. Review and Discuss: Concept for a Collaborative Approach to Living Donor Data Collection
2. Member Recognition

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

### **1. Review and Discuss: Concepts for a Collaborative Approach to Living Donor Data Collection**

The Committee reviewed and discussed the paper they seek to submit for summer 2023 public comment, *Concepts for a Collaborative Approach to Living Donor Data Collection*.

#### Summary of discussion:

**Decision #1:** The Committee recommended a final version of their concept paper, *Concepts for a Collaborative Approach to Living Donor Data Collection*, be submitted for summer 2023 public comment period.

A member suggested for the executive summary to be more detailed and pragmatic in its explanation of the concepts. The Vice Chair agreed and suggested the executive summary have an explicit sentence outlining the collaborative approach and shared responsibility of the OPTN and SRTR. An SRTR representative suggested to the concept paper state that the Living Donor Collective is a task in their contract with HRSA.

A member suggested to mention the SRTR's Task 5 Consensus Conference in the *Need for Long-Term Living Donor Data Collection* section in order to cite the input from that consensus conference regarding the need for understanding lifelong implications of living donation. The member also suggested to mention that a majority of states also have living donor protection acts.

The Vice Chair suggested that the paper should be clear regarding the differences between SRTR being able to interface directly with living donor candidates and living donors compared to the OPTN having authority of transplant programs per policy requirements.

Another member asked whether living donors have to consent to have their data used in data linkages. An SRTR representative responded that both the SRTR and OPTN are public health authorities which means informed consent is not needed. The SRTR representative advised the Committee to be prepared to speak to those potential concerns during regional meeting presentations.

The Vice Chair stated that the concept paper should emphasize that the data collection is a realignment for the purpose of improving efficiency, reducing redundancy, and acquiring key data. The Vice Chair

stated that the concept paper should be very clear that the concepts are not intended to be an added data collection but rather a shift and realignment in order to minimize the redundancy and limit burden.

The Committee suggested revisions to some graphics in the concept paper in order to better articulate and visualize their proposed concepts. Members proposed additional suggestions to turn the summary of their discussions regarding living donor candidate definition into a visualization in order for the community to understand the balanced approach the Committee took when deciding a proposed definition.

Another member stated it is not clear to them whether living donor candidates who are denied during evaluation are also followed up long-term. An SRTR representative stated that understanding sociodemographic and clinical factors of living donor candidates who are denied during evaluation will help further understand barriers and access to living donation. The SRTR representative added that following up with these individuals long-term will also help provide an understanding whether some exclusions may not be clinically relevant.

Next steps:

The Committee's concept paper will be finalized and submitted to the summer 2023 public comment period.

**2. Member Recognition**

The Chair and Committee members thanked the departing Committee members their service and contributions.

**Upcoming Meeting**

- July 12, 2023 (teleconference)

## Attendance

- **Committee Members**
  - Aneesha Shetty
  - Ashtar Chami
  - Camille Rockett
  - Dylan Adamson
  - Henkie Tan
  - Hoylan Fernandez
  - Mary Beth Stephens
  - Nahel Elias
  - Nancy Marlin
  - Mark Payson
  - Stevan Gonzalez
  - Tyler Baldes
  - Vineeta Kumar
- **HRSA Representatives**
  - Adriana Martinez
  - Marilyn Levi
  - Mesmin Germain
  - Vanessa Arriola
- **SRTR Staff**
  - Caitlyn Nystedt
  - Krista Lentine
- **UNOS Staff**
  - Carol Covington
  - Jennifer Wainright
  - Kim Uccellini
  - Laura Schmitt
  - Meghan McDermott
  - Ruthanne Leishman
  - Sam Weiss
  - Stryker-Ann Vosteen
- **Other Attendees**
  - Chris Woody