

**OPTN Living Donor Committee  
Meeting Summary  
August 14, 2024  
Conference Call**

**Steve Gonzalez, MD, Chair  
Aneesha Shetty, MD, Vice Chair**

## **Introduction**

The OPTN Living Donor Committee (“Committee”) met via Cisco WebEx teleconference on 08/14/2024 to discuss the following agenda items:

### **1. OPTN Living Donor Registration Data Elements**

The following is a summary of the Committee’s discussions:

#### **1. OPTN Living Donor Registration Data Elements**

No decisions were made.

#### Summary of Presentation:

The Chair discussed his presentation to the Board discussing project updates for Improving Efficiency of Living Donor Data Collection. This included an overview of upcoming work about decision data collection and a granular review of the 3 OPTN data forms. He also discussed prioritization of living donors in continuous distribution proposals.

#### Summary of discussion:

Support staff discussed updates to the phased approach of the project, stating that phase 1 will include minimal changes allowing creation of the long-term SRTR data collection and analysis. Staff asked the committee to consider which data elements currently collected by the SRTR should be collected by the OPTN. They continued that elements currently collected by the OPTN pre-donation will be collected for all living donor candidates and that decision-making should include the most critical information. The Chair stated that the OPTN data forms are increasing burden, and therefore, keeping information to the critical minimum will help with the transition process.

A Scientific Registry of Transplant Recipients (SRTR) representative asked the Chair if there should be baseline clinical information gathered later to fill in data gaps. He responded that extraneous information shouldn’t be gathered if the SRTR wouldn’t be able to follow-up with it long-term. A committee member asked if the SRTR is properly staffed for the proposed expansions of data collection. Another SRTR member stated that they are working on a presentation of their expansion plans and have been discussing their staffing needs. A HRSA representative stated that they commit to transparency and expect continued HRSA support of this work. The committee Vice Chair clarified that the plan is to reduce burden on the OPTN form and shift some follow-up to the SRTR. An SRTR representative stated that the SRTR form developed by their steering committee should be used as a starting model for the OPTN rather than an expectation of a strict framework and that the SRTR will be focused on long-term follow-up.

The Vice Chair mentioned that important data elements could include “stable” elements that likely will stay accurate over time. A member asked about data collection regarding domino donation, and the Chair said that this collection would be included in living donor data.

Staff continued with survey feedback about demographic data collection and stated respondents to the survey indicated that preferred method of contact is essential to collect and address/contact information changes over time. Although respondents marked that donation financial barriers should be included in phase 1, the committee recognized that this may be looked at by the decision data workgroup first. The Vice Chair also acknowledged that financial hardship data may change over time, and that “other contacts” should be marked as a tick box rather than a free-text field. The committee discussed secondary contact information fields.

For clinical information, support staff presented that clinical information should capture risks associated with living donation. The Chair asked how much clinical data relies on laboratory data, especially since programs vary on their evaluation of a candidate. A member asked how much of the clinical data can be collected from insurance companies while also recognizing that not all potential donors have insurance. The Chair and SRTR discussed whether some data can be collected from insurance or pharmacies. A member asked if blood pressure would be manually entered and if hypertension would need to be marked from there. The committee discussed definitions of marijuana use and whether collecting marijuana use data is essential. The Vice Chair stated that she did not think marijuana use is an essential data element, and that blood pressure reporting can vary, and therefore blood pressure medication reporting may be a more accurate measure for hypertension. The Vice Chair followed up that the details of conversations could be collected into a guidance document for data collection.

#### Next steps:

The committee decided on the following demographic data elements for phase 1: “Is the mailing address the same as the home address?” “Secondary/other contact?” “Preferred method of contact?” “Is donation a financial hardship?”

The Committee will discuss the remaining data elements at the next meeting.

#### **Upcoming Meetings:**

- September 12<sup>th</sup>, 2024 (In person)

## Attendance

- **Committee Members**
  - Aneesha Shetty
  - Alexandra Shingina
  - Anita Patel
  - Ashtar Chami
  - Dylan Adamson
  - Ginger Ireland-Hoffman
  - Milton Mitchell
  - Laura Butler
  - Michael Chua
  - Nancy Martin
  - Nawraz Shawir
  - Steve Gonzalez
  - Tiffany Caza
  - Trysha Galloway
- **SRTR Representatives**
  - Avery Cook
  - Caitlyn Nystedt
  - Katie Siegert
  - Krista Lentine
- **HRSA Representatives**
  - Mesmin Germain
  - Jim Bowman
  - Marilyn Levi
- **UNOS Staff**
  - Jamie Panko
  - Kieran McMahan
  - Laura Schmitt
  - Meghan McDermott
  - Sam Weiss
  - Jen Wainright
  - Sara Rose Wells