

## **OPTN Living Donor Committee Decision Data Workgroup**

### **Meeting Summary**

**August 19, 2024**

**Conference Call**

**Aneesha Shetty, MD, Chair**

### **Introduction**

The OPTN Living Donor Committee Decision Data Workgroup (“Workgroup”) met via Cisco WebEx teleconference on 08/19/2024 to discuss the following agenda items:

- 1. Background Information**
- 2. Tasks of the Workgroup**

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

### **1. Background Information**

No decisions were made.

### Summary of Presentation:

The Workgroup chair gave an in-depth overview of the project background. She reviewed OPTN and Scientific Registry for Transplant Recipients (SRTR) current living donor candidate data collection. She discussed that this Workgroup will collaborate with the SRTR Living Donor Collective to register and collect donation decision data through the OPTN. The SRTR will follow up long-term with donors and perform analysis of barriers and long-term outcomes of living donation.

The Chair reviewed the current 3 forms used by the OPTN – pre-donation, perioperative period, and post-donation. She also discussed current SRTR data collection on donation decision as an outline for this project’s work. She showed a workflow outlining the proposed future state of decision data collection between the OPTN and SRTR. The Chair discussed the project details as outlined in the 2023 concept paper, with mention of the 2024 revisions that refined the project goals and scope. Further, she mentioned the current timeline of the Workgroup’s meetings.

The Chair reviewed public comment feedback from the 2023 concept paper, including privacy concerns around data collection stemming from the confidential nature of turndowns or reasons why a candidate might back out of wanting to be a living donor. The Chair then asked for the Workgroup to consider data collection options such as grouped donation decision reasons, free-text options, and a decline-to-answer option. She also reminded the committee that data collection should not become too burdensome on the transplant programs, and that these forms could be expanded from just kidney and liver data collection.

## 2. Tasks of the Workgroup

No decisions were made.

### Summary of Presentation:

The Workgroup began discussions on tasks of the group.

### Summary of discussion:

The Living Donor Committee Chair asked the Workgroup what they think are challenges that may arise with this project. A member answered that the living donor definition surrounding candidacy is somewhat undefined. The LD Chair responded that they have settled on anchoring their candidacy definition in policy. The Workgroup Chair stated that data elements around types of donations (familial, altruistic, etc.) could be included in data collection. A member said that data reports could be looked at to eliminate some burden of data collection. A member asked if potential donors who did not initially donate could come back to their same data form. An SRTR representative stated that they have considered a time limit on returning to data collection forms.

Another SRTR representative stated that some potential donors who were not able to donate like to stay involved in the process in whichever ways they can. A member said that a control group to compare data would be helpful when it comes time for analysis. The Workgroup Chair mentioned the importance of including a data field about potential donors who no longer wish to be contacted. A member discussed the importance of balancing data collection with patient safety. Another member mentioned that the forms should be set up in a way that is straightforward so as to not force the coordinators to make personal judgement calls.

### Next steps:

Staff reviewed next steps, including an SRTR presentation at the next Workgroup meeting.

### **Upcoming Meetings:**

- TBD

## Attendance

- **Committee Members**
  - Aaron Ahearn
  - Aneesha Shetty
  - Amy Olsen
  - Ashley Hamby
  - Gregory McKenna
  - Jennifer Peattie
  - Katie Dokus
  
  - Lauren Darensbourg
  
  - Michael Chua
  - Obi Davies Ekwenna
  - Julie Prigoff
  - Reza Saidi
  - Steve Gonzalez
  - Tiffany Caza
  - Trysha Galloway
- **SRTR Representatives**
  - Caitlyn Nystedt
  - Katie Siegert
  - Krista Lentine
- **HRSA Representatives**
  - Mesmin Germain
- **UNOS Staff**
  - Jamie Panko
  - Kieran McMahan
  - Laura Schmitt
  - Meghan McDermott
  - Sam Weiss