

OPTN Living Donor Committee Decision Data Workgroup

Meeting Summary

October 10, 2024

Conference Call

Aneesha Shetty, MD, Chair

Introduction

The OPTN Living Donor Committee Decision Data Workgroup (“Workgroup”) met via Cisco WebEx teleconference on 10/10/2024 to discuss the following agenda items:

- 1. Timeline Discussion**
- 2. Living Donor Candidate Definition**
- 3. Data Elements Review**

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

1. Timeline Discussion

No decisions were made.

Summary of Presentation:

The Workgroup Chair reviewed the project timeline and items still needed for the proposal. Next, the Chair presented the decision to continue with the January public comment timeline, which the full Committee had requested at their prior meeting. The Workgroup saw the other timeline options, including a request for feedback, special public comment period, or summer public comment cycle. The Chair mentioned that the Committee chose to move forward with January public comment because of the substantial amount of work that had already been put into the proposal. Further, the Committee felt that prior feedback received from the project’s concept paper was sufficient.

Summary of discussion:

The Chair asked for feedback from the workgroup regarding the January proposal timeline. A Data Advisory Committee (DAC) representative asked which entities would need to approve this project, and staff replied that this proposal would need approval from Office of Management and Budget (OMB) and Health Resources and Services Administration (HRSA). Staff said the OPTN policy steps for this project would be the same at whatever point the proposal goes out for public comment, and instead the Workgroup should focus on the group’s ability to complete the project within the suggested timeframe.

A Workgroup member asked for the goals of the public comment period, and if the group would like to gain more feedback on the data elements or approval on the general work of the project. The Chair replied that it should be both. A DAC representative stated that this proposal would also need to be seen by their advisory committee.

A member asked how much of a finished product would need to be done prior to January, and the Chair replied that this would involve reviewing all data elements and operationalizing them into the decision data form. A DAC representative reminded the Workgroup about data burdens and feasibility of data

collection, especially within the short timeline. The Chair reviewed the data elements that still need to be discussed.

2. Living Donor Candidate Definition

No decisions were made.

Summary of Presentation:

The Chair reviewed the Committee’s discussion about choosing a living donor candidate definition. She mentioned that the definition should be mindful of data entry burdens while also being inclusive of necessary data to accomplish the goals of the project. The Committee had previously agreed upon the following regarding the definition of a living donor candidate:

- Data collection should include those who have begun an LD evaluation but “fell out” off the process
- Should be anchored in OPTN policy
- Will cover in-person clinic and telehealth appointments
- Does not include those screened out by online screening tools
- Does not require programs to complete additional testing beyond regular program practices

The Chair reviewed the living donor candidate definition that was recommended by the Committee:

- 14.2 Independent Living Donor Advocate (ILDA) Requirements
 - “For any living donor who is undergoing evaluation for donation...”

The Chair mentioned that this definition could be used for mirroring ILDA language, which roots the living donor definition for the project into OPTN policy. It could also give a framework for program monitoring.

Summary of discussion:

The workgroup heard that according to policy, ILDA’s must be assigned prior to initiation of the evaluation process. This option is rooted in OPTN policy and programs are already monitored for ILDA practices. A DAC representative said that ILDA language might need additional clarity, such as whether this is referring to scheduling to meet with an ILDA or they have already met with one. Staff responded that this definition option would not include monitoring ILDA meetings, but just be on a similar timeline as ILDA practices.

A member said this definition should outline if an ILDA unsuccessfully attempts contact. The Committee Chair stated the importance of allowing center flexibility in the definition, and rooting the definition in current OPTN policy would help to not create additional burdens on current practices. A member asked if centers typically have an ILDA contact a potential living donor before blood testing, and a member responded that labs may be done before ILDA contact. The Workgroup agreed that it may be important to collect decision data on a potential living donor who “fell out” after an ILDA assignment but before labs were completed.

A staff member discussed ILDA monitoring practices, and the Workgroup Chair asked if monitoring includes ILDA contact before evaluation. Staff responded that this is monitored. A member said that the definition could be rooted in “first ILDA contact.” Staff said that monitoring practices, including monitoring of where the decision data collection would begin, can be decided by the committee.

Next steps:

The Committee and Workgroup will continue the definition discussion.

Upcoming Meetings:

- 10/24/24

Attendance

- **Committee Members**
 - Aaron Ahearn
 - Aneesha Shetty
 - Amy Olsen
 - Jennifer Peattie
 - Katie Dokus
 - Julie Prigoff
 - Reza Saidi
 - Steve Gonzalez
 - Trysha Galloway
- **SRTR Representatives**
 - Katie Siegert
 - Caitlyn Nystedt
 - Avery Cook
- **HRSA Representatives**
 - Mesmin Germain
 - Allison Hutchings
 - Shannon Dunne
 - Arjun Naik
- **UNOS Staff**
 - Jamie Panko
 - Kieran McMahon
 - Laura Schmitt
 - Sam Weiss
 - Sara Langham