

OPTN Living Donor Committee Decision Data Workgroup

Meeting Summary

November 21, 2024

Conference Call

Aneesha Shetty, MD, Chair

Introduction

The OPTN Living Donor Committee Decision Data Workgroup (“Workgroup”) met via Cisco WebEx teleconference on 11/21/2024 to discuss the following agenda items:

- Updates on Project/Level Set on Approach
- Review and Discuss Mockup

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

1. Updates on Project/Level Set on Approach

No decisions were made.

Summary of Presentation:

The Workgroup Chair reviewed updates to the project since their last meeting. This included Data Advisory Committee leadership providing feedback and strengthening project data collection, the OPTN Executive Committee hearing a project update, and the Committee’s affirmant of the Summer 2025 public comment timeline. The Committee also agreed to focus on the big picture to help the workgroup build data collection, such as baseline clinical and demographic data, along with donation decision data.

Conversations with DAC included:

- The importance of getting the project right for the community
- The importance of establishing critical data collection quickly and correctly
- Scientific Registry of Transplant Recipients (SRTR) vs OPTN data collection

The Workgroup Chair also reminded the Workgroup to focus on the project impact on target populations. She stated that the Committee discussed risks and benefits, with items including:

- Improving informed consent
- Informing policy related to exclusions for living donations
- Providing insight into the selection criteria for individual programs
- Inform future initiatives to provide support for living donor candidates

As well as barriers:

- Examining equity
- Providing insight into selection criteria for individual programs
- And identifying where there are possible areas to provide additional support to living donor candidates in evaluation process

2. Review and Discuss Mockup

No decisions were made.

Summary of Presentation:

An OPTN data management staff member reviewed the mockup. She discussed the timeline of “form B,” or the donation decision data form. This would collect data from candidates who dropped out past evaluation beginning but before donation. She mentioned that SRTR data suggestions are being used for scaffolding. She showed that clinical information could be collected on all candidates because it will also be included in form A2, or initial candidate information.

Summary of discussion:

The Committee Chair said it made sense that some baseline information could be collected for all candidates. He said there may be organ-specific baselines for all candidates. A member asked about living donor program volume, and staff responded that it varied. Staff also reminded that this form would include anyone who has begun evaluation past screening. A member said that this could be difficult because of varieties of program volumes. The Workgroup Chair said this definition can be adjusted later.

The Workgroup discussed the following:

Data Element	Include on Form B: Y/N	Discussion/Reasoning
Living Donor Institution	Yes	Important to candidate data collection.
Donor Name (last, first, middle)	Yes	A member said “donor candidate” is better wording. Important to candidate data collection.
Donor SSN	Continuing conversation	<p>Staff said SSN is important to individuals getting evaluated at multiple centers and information linking. A member said that programs should notify candidates about their SSN being collected. SRTR staff said data collection policies may be site-by-site and the SRTR uses SSNs to sort data.</p> <p>The WG Chair said that candidate reluctance, lack of social security number, and variations in program practices, may limit SSN data collection.</p> <p>A member said SSN collection poses a risk for data breaches.</p>
Donor DOB, birth sex, ethnicity, and race	Yes	<p>Important to candidate data collection.</p> <p>A member said “unknown” options should be added for race/ethnicity if a candidate doesn't see a social worker for race/ethnicity clarification before dropping out.</p> <p>Wording suggestions included “candidate declined.”</p>

Data Element	Include on Form B: Y/N	Discussion/Reasoning
<p>Organ type:</p> <p>Left/right kidney, pancreas segment, liver segment, heart, left/right lung lobe, domino whole liver, VCA.</p>	<p>Yes</p>	<p>A member said right/left might not be available information at time of form.</p> <p>A member said pediatrics/adult should be specified.</p> <p>The workgroup decided to remove removing heart and liver domino donation options.</p> <p>The workgroup added option for “non-directed” for intended recipient along with pediatrics and adults.</p>
<p>Clinical information collected on all:</p>		
Data Element	Include on Form B: Y/N	Discussion/Reasoning
<p>Diabetes (Y/N/Unknown)</p> <p>Hypertension (Y/N/Unknown)</p> <p>History of kidney stones (Y/N/Unknown)</p> <p>Family history of kidney disease (Y/N/Unknown)</p>	<p>Continuing conversation</p>	<p>The workgroup decided to call the category with these diagnoses as “medical history,” followed by “family history” “surgical history” and “psychosocial history.”</p> <p>The WG Chair added that these reasons do not necessarily have to be the rule-out options.</p> <p>A member said this could be divided into “patient reported” and “program reported.” A DAC member said this might not be possible for coordinators to distinguish that information. The WG decided not to differentiate these.</p> <p>Members said that there are other, more common reasons, for a candidate to not be approved for donation.</p>

Upcoming Meetings:

- 12/19/24

Attendance

- **Committee Members**
 - Aaron Ahearn
 - Aneesha Shetty
 - Amy Olsen
 - Annie Doyle
 - Ashley Hamby
 - Gregory McKenna
 - Michael Chua
 - Jennifer Peattie
 - Katie Dokus
 - Julie Prigoff
 - Steve Gonzalez
 - Tiffany Caza
 - Trysha Galloway
- **SRTR Representatives**
 - Katie Siegert
 - Caitlyn Nystedt
 - Avery Cook
- **HRSA Representatives**
 - Nawraz Shawir
- **UNOS Staff**
 - Jamie Panko
 - Kieran McMahon
 - Sam Weiss
 - Sara Langham
 - Cole Fox
 - Lauren Mooney
 - Sara Rose Wells