

**OPTN Data Advisory Committee  
Meeting Summary  
April 14, 2025  
Conference Call**

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## **Introduction**

The OPTN Data Advisory Committee (DAC) met via WebEx teleconference on 04/14/2025 to discuss the following agenda items:

1. Welcome, reminders, and agenda review
2. 2<sup>nd</sup> Check-in, Living Donor Committee: *Update and Improve Efficiency in Living Donor Collection*
3. Other Committee business
4. Open forum
5. Closing remarks

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

### **1. Welcome, reminders, and agenda review**

The DAC Chair welcomed the members and let them know that the meeting would primarily focus on reviewing the OPTN Living Donor Committee's (LDC) proposed data collection project. The Chair mentioned that the LDC is proposing a very large data collection effort.

### **2. 2<sup>nd</sup> Check-in, Living Donor Committee: *Update and Improve Efficiency in Living Donor Collection***

The LDC Chair and Vice Chair joined the meeting. The LDC Chair presented the proposed data collection and reminded the DAC members that this was the project's second check-in. Based on the discussion, the DAC members did not provide an endorsement of the data collection. The DAC Chair invited the LDC Chair and Vice Chair to attend DAC's 05/12/2025 meeting and continue the discussion.

#### Summary of discussion:

Decision #1: DAC chose not to endorse the Living Donor Committee's data collection as currently proposed.

The LDC Chair said the project aims to improve the efficiency of living donor data collection and involves collaboration with various OPTN committees and workgroups, as well as the SRTR Contractor. The presentation highlighted how LDC saw the importance of DAC's feedback to ensure the project's success.

LDC proposes splitting the data collection effort into two phases. Phase 1 focuses on collecting data on potential living donors who do not proceed to donation in order to better understand the barriers to living donation. The LDC Chair acknowledged that the project involves collecting many new data elements and modifying existing data elements, which will increase collection and reporting for OPTN members. The LDC Chair also explained that the proposal attempts to minimize the impact of the

increased collection and reporting on recovery hospitals where it is possible. The LDC Chair also noted that the benefit of having the proposed information will expand knowledge on long-term outcomes of living donors. Phase 1 involves collaboration with the SRTR Contractor and aims to use the existing OPTN data collection framework with minimal changes. The LDC is addressing Phase 1 in the proposal they plan on submitting as part of the next OPTN public comment period.

Phase 2 of the project involves revising outdated data collection forms and refining the framework established in Phase 1. Phase 2 will require changes to existing data elements and the creation of new forms for potential living donors.

The LDC Chair provided a detailed overview of the data collection triggers and workflow. LDC proposes defining a potential living donor as a living individual who intends to donate an organ but from whom an organ has not yet been recovered. A new OPTN data collection form will be created for potential living donors who do not proceed to donation. The form will capture essential demographic and clinical information, decision dates, and reasons for not donating. Data collection will start at the first in-person evaluation appointment with the transplant program and will close when a decision is made not to proceed with donation by either the potential living donor or the transplant program. The project's collaboration with the SRTR Contractor was emphasized by the LDC Chair, particularly regarding the collection of contact information for follow-up purposes. The importance of this data for long-term follow-up was highlighted, and suggestions were made to ensure clear communication with potential donors.

Following the presentation, DAC members provided feedback on various aspects of the proposed data collection forms. The members' primary concern was about the burden of data collection that would be imposed on transplant programs. Of particular concern was that many of the proposed data elements would appear in the notes sections of patients' electronic health records (EHR), rather than as discrete data fields that could be efficiently extracted from the EHRs. The DAC members wanted to know if the LDC had made an effort to identify the extent to which the proposed data elements appeared in EHRs already versus appearing in notes. DAC members pointed out that transplant programs can work with their EHR vendors to efficiently map and extract such data, but that was not what the LDC project appeared to be proposing.

DAC members also stressed that LDC needs to provide clear data definitions and specific medical history details to ensure accurate data collection. Specific feedback was provided about several proposed data elements. For instance, DAC members discussed the need for specificity in collecting information about diabetes, hypertension, and cancer, such as distinguishing between type 1 and type 2 diabetes and including hemoglobin A1C levels. The inclusion of an "unknown" option was debated, with concerns about its utility and the potential for it to be a default choice. There was also discussion of the need for a clear definition of 'alcohol consumption' and the inclusion of the following drop-down options was discussed: 'yes,' 'no,' and 'unknown.' DAC members suggested that if the answer is 'no,' then there should be no need to complete a zero range. Concerns were raised about the feasibility of extracting data from pathology reports, given the variability in how different pathologists document findings. The need for clear and consistent data extraction processes was emphasized. The suggestion to separate medical and surgical contraindications was discussed, with members noting the importance of distinguishing between different types of contraindications for accurate data analysis.

OPTN Contractor staff asked whether DAC would consider endorsing the proposed data collection. The DAC Chair responded that, based on the discussion, the Committee would like to continue iterating on the proposal with the Living Donor Committee to determine, what if any of the DAC suggestions could be implemented. The Chair continued that the DAC members concerns had not been completely assuaged and so it was probably premature to consider an endorsement at this stage. The Chair stated

that the Committee would provide LDC leadership with a summary of DAC's concerns and recommendations and perhaps the Living Donor Committee could consider whether or not to address the concerns and recommendations. The DAC Chair emphasized the importance of making the data collection process feasible and meaningful for transplant centers and living donors.

Next steps:

OPTN Contractor staff will synthesize the DAC members' feedback provided during the meeting and provide it to the Living Donor Committee for further review. The goal is to refine the proposal and ensure it is practical and impactful before moving to public comment.

### **3. Other Committee business**

Because the discussion of the OPTN Living Donor Committee's project took up the entirety of the meeting time, there was no discussion of other DAC business.

### **4. Open forum**

No requests from the public were received prior to the meeting to address the Committee during open forum.

### **5. Closing remarks**

The DAC Chair thanked the Committee members for their participation and valuable insights.

### **Upcoming Meetings** (Meetings start at 3:00 pm (ET) unless otherwise noted)

- ~~July 8, 2024~~
- ~~August 12, 2024~~
- ~~September 10, 2024 — In-person meeting, Detroit, MI, 8:00 am — 3:00 pm (ET)~~
- ~~October 21, 2024~~
- ~~November 18, 2024~~
- ~~December 4, 2024 10:30 am — 2:30 pm (ET) — HHS Data Collection Directive Meeting~~
- ~~December 9, 2024 11:00 am (ET)~~
- ~~January 12, 2025~~
- ~~February 10, 2025~~
- ~~March 10, 2025~~
- ~~April 14, 2025~~
- May 12, 2025
- June 9, 2025

## Attendance

- **Committee Members**
  - Jesse Schold
  - Lisa McElroy
  - Rebecca Baranoff
  - Kate Giles
  - Michael Marvin
  - Christine Maxmeister
  - Nancy McMillan
  - Paul MacLennan
  - Jennifer Peattie
  - Julie Prigoff
  - Meghan Schaub
  - Alicia Skeen
  - Lindsay Smith
  - Allen Wagner
- **HRSA Representatives**
  - Shantel Delgado
- **SRTR Staff**
  - Avery Cook
  - Allyson Hart
  - Jon Miller
  - Caitlyn Nystedt
  - Kate Siegert
  - Jon Snyder
- **UNOS Staff**
  - Brooke Chenault
  - Jonathan Chiep
  - Cole Fox
  - Jesse Howell
  - Sara Langham
  - Lindsay Larkin
  - Eric Messick
  - Lauren Mooney
  - Nadine Rogers
  - Sam Weiss
  - Sara Rose Wells
- **Other Attendees**
  - Stevan Gonzalez
  - Aneesha Shetty