

OPTN Living Donor Committee Decision Data Workgroup

Meeting Summary

April 17, 2025

Conference Call

Aneesha Shetty, MD, Chair

Introduction

The OPTN Living Donor Committee Decision Data Workgroup (“Workgroup”) met via Cisco WebEx teleconference on 4/17/2025 to discuss the following agenda items:

- Continue Review and Discuss Mockup: Form B

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

Announcements

None.

1. Continue Review and Discuss Mockup: Form B

Summary of discussion:

The workgroup Chair summarized feedback about the data collection project provided by the OPTN Data Advisor Committee (DAC) on 4/14/2025. The DAC appreciated the intent of safeguarding donor health and obtaining long-term follow-up information but had concerns about the administrative burden on centers. They requested changes to specific data elements and suggested sharing perspectives on the ratio between potential living donor candidates and actual living donors. The Committee also highlighted the difficulty of extracting information from clinician notes compared to discrete fields in electronic medical records (EMRs).

The workgroup Chair elaborated on the DAC's feedback, noting that the committee liked the product in general but had concerns about the administrative burden. They suggested that workgroup and committee members share their perspectives on the ratio of potential living donors to actual living donors, which could help understand the administrative burden better. The Living Donor Committee Chair added that understanding this ratio is important in the context of when data collection on potential living donors begins, specifically when they come in person for evaluation.

Review of Form B

Staff reviewed Form B, highlighting comments from the DAC in purple and items that needed further discussion. She emphasized the importance of considering how to ask questions in a way that makes data retrieval easier for living donor centers. Staff noted that the DAC had removed many clinical elements from their referral and evaluation form to reduce the burden and suggested the workgroup consider similar changes.

Intended Recipient Field

The group discussed the intended recipient field, considering separating directed and non-directed donations, and further categorizing directed donations into adult/pediatric and biologically related/unrelated. They debated whether to simplify the field to just directed and non-directed for ease

of data collection and mapping. The workgroup Chair explained that separating the fields would allow for more effective analysis. The Living Donor Committee Chair clarified that the separation would involve creating child fields for directed donations. Ultimately, they agreed to keep it simple with just directed and non-directed options.

Previously Evaluated for Candidacy

The group questioned the value of the field asking if a donor had been previously evaluated for candidacy. They discussed the possibility of determining this information on the back end using social security numbers and patient IDs. Two members both agreed that this information could be identified on the back end, and the group decided to eliminate the field from Form B.

Previous Donation

A suggestion from the DAC to add a question about previous donations was discussed. The group considered whether it was necessary to capture information about donors who had previously donated a different organ. They decided that this information could also be identified on the back end and agreed not to include the question in Form B.

Diabetes

The group discussed the diabetes section, considering comments about the choice list and the difficulty of pulling information from the system. They debated whether to keep the unknown option and how to define diabetes. Aneesha suggested that the unknown option might not be useful for analysis. A member raised the point that some potential donors might not have their medical history fully documented. The group decided to simplify the field to three independent questions: diabetes (yes/no), A1C value, and history of gestational diabetes (yes/no). They agreed to move the A1C value to the labs section.

Hypertension

Similar to the diabetes discussion, the group considered simplifying the hypertension field. They discussed the importance of capturing whether donors were on pharmacological treatment for hypertension. The workgroup Chair noted that the OPTN guidelines allow well-controlled hypertensive donors to donate. The group decided to keep it to two questions: hypertension (yes/no) and pharmacological management (yes/no).

Conclusion

Due to time constraints, the group acknowledged that they could not complete the review of all remaining fields. Staff suggested scheduling another workgroup meeting to finalize the discussions. The group agreed that another meeting was necessary to ensure thorough review and completion of Form B. The meeting concluded with a reminder to stay tuned for the next meeting invite.

Summary of Decisions

Section	Decision
Intended Recipient Field	Simplify to two options: directed and non-directed

Section	Decision
Previously Evaluated for Candidacy	Eliminate the field; determine on the back end using social security numbers and patient IDs
Previous Donation	Do not include the question; identify on the back end
Diabetes	Simplify to three independent questions: diabetes (yes/no), A1C value, and history of gestational diabetes (yes/no); move A1C value to labs section
Hypertension	Simplify to two questions: hypertension (yes/no) and pharmacological management (yes/no)

Next Steps:

Staff will send the updated mock up document of Form B. Staff will send a request to this workgroup and to the living donor committee with a request for members to share living donor and potential living donor member numbers to assess additionally burden.

Upcoming Meetings:

- 5/8/2025, 12pm-1pm ET, teleconference

Attendance

- **Committee Members**
 - Amy Olsen
 - Trysha Galloway
 - Annesha Shetty
 - Jennifer Peattie
 - Kate Dokus
 - Michael Chua
 - Tiffany Caza
 - Stevan Gonzalez
 - Annie Doyle
 - Gregory McKenna
 - Julie Prigoff
- **SRTR Representatives**
 - Caitlyn Nystedt
 - Katie Siegert
- **HRSA Representatives**
 - None
- **UNOS Staff**
 - Sara Langham
 - Emily Ward
 - Lauren Mooney
 - Laura Schmitt
 - Sara Rose Wells
 - Asma Ali
 - Cole Fox
 - Samantha Weiss
 - Melissa Gilbert