

OPTN Living Donor Committee Decision Data Workgroup

Meeting Summary

March 6th, 2025

Conference Call

Aneesha Shetty, MD, Chair

Introduction

The OPTN Living Donor Committee Decision Data Workgroup (“Workgroup”) met via Cisco WebEx teleconference on 3/6/2025 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

Please see the decisions below.

Summary of discussion:

Decision Information

1. Data Element: reason for not donating

Decision: The LDR (or Form 2) should continue capturing those who go under anesthesia but do not donate. Keep multi-select option format. Add “Donor Choice or Transfer” as a reason for not donating, but then under “Donor Choice,” add the option “donor transferred to a different center.” Also change “Donor Choice” field to “Donor Choice or Transfer.” Remove “other as an option under “Reason for Not Donating.”

Reasoning: The current feedback form has a question about anesthesia. Should this be included here? How can we include when candidate goes under anesthesia but did not donate. This was also a part of the living donor registration form (LDR). The Chair commented that maybe being given anesthesia could be the threshold for considering donating. Right now, the LDR generates, but it is not written into policy. Staff is working to track down the history (early 2000s) and documentation around why this occurs. A member commented that he recently had this occur at his center and emphasized it is a reportable event. He commented that these are outcomes and not reasons why people don’t donate. By definition, they were not turned down. Sometimes, these candidates have a reaction to the anesthesia, but then go on to donate at a later time.

The group discussed the options “other: undocumented or transferred to a different center.” Where should these two cases be located? The fewer options for “other,” the better. A member commented that undocumented or international could fall under the psychosocial section. Additionally, transferring centers could fall under Donor Choice. What about living donor liver

swaps? That would not be “donor choice.” Sometimes living donors do a workup at one site and then donate at another site. Donor transfer should be a separate option from donor choice. There can be one category, “donor choice or transfer” with another child category under this with a subcategory “transferred to another center.”

2. Data Element: wording for “Select Reason for Not Proceeding with Donation “and options Decision: Group likes this and wants to keep it and all options (already on the sheet) should stay. Multiselect should be enabled.
Reasoning: Does the group want to keep this wording or change it?

3. Data Element: Child field of reasons for not donating: Medical/Surgical Contraindications
Decision: Multi select should be possible. Remove “History of Chronic Pain” and replace with “Medication.” Keep “Hypertension” broad. Add “Gastrointestinal Abnormalities.” Add “Surgical history”
Reasoning: Is there additional information, like numbers for hypertension that should appear if one of these is selected? A member asked if multi select is possible. Yes. Also, for “Decision Information,” multi select will be enabled. An example is selecting “Psychosocial” and also “Medical/Surgical.” History of chronic pain may need to be more specific. Chronic narcotics may need to be an option in addition to chronic pain. It may need to be broader to capture other medication. Examples are heart medications or lithium. This is also under the “Psychosocial” category as “Substance use or abuse,” but not called out specifically. The group feels that the option “medication” is enough for the purposes of understanding why candidate did not donate. The group considered adding child fields like narcotics, and nephrotoxic medications, but the burden on IT teams at centers and on data entry employees is high and this is too “in the weeds.”

The group considered the option “Hypertension.” Knowing what considered unacceptable hypertension to donate would be helpful, but this information is not known. This is difficult to collect and fill out this data. Leaving it broad is good for now, even if there will be a lot of public comment. Surgical history can be related to this or not but can rule someone out and be important to know. An example is someone being ruled out due to history of a right hepatectomy. A member suggested being more specific by adding “Abdominal surgery history.” Broad is better because there are other surgeries besides abdominal surgeries, like lung. Education about this will also be important for this option.

A member asked if “impaired glucose tolerance” might want to be captured. One member mentioned metabolic syndrome as being a similar option. This called also be “Pre diabetes and Diabetes” to avoid adding subfields.

A member commented that many living donors have gastrointestinal issues and sometimes need to have second surgeries. It might even be a reason to rule out a donor. Add this.

4. Data Element: Continued Medical/Surgical information
Decision: Add “genetic disorders or family history.” Remove “family history of cancer” because it is covered in the previously new added option. Also just label “kidney stones” and not “history of kidney stones” (more clear). Change to “infection transmission risk” – shorter and more clear. Change to “anatomic or vascular variants” (not abnormalities – incorrect term). Add neurologic abnormalities. Add “anticipated remnant volume for liver.”

Reasoning: Staff asked this should be included and what is the intent. There are two different things: a potential donor may have a genetic disorder or may have a family history of the disorder with no signs of it at present. There is also a "family history section" in the Medical/Clinical section of the form. It is asking about kidney or liver disease.

The group additionally reviewed a few options for wording/semantics. The group would like to account for mismatched organs by adding an option "Size mismatch/quality." The group discussed possibly grouping (all together) three options:

- Anatomic or vascular variants
- Anticipated remnant volume for liver
- Size or age mismatch / quality

The group would like to add a public comment feedback question about it and if this level of detail is needed. The group added that a data request for anatomical variations (donation decision form) would be helpful. Staff will follow up with leadership about this request.

It would still probably be good to leave "other/specify" to learn what to add as an option in the future. A member suggested to also add neurologic abnormalities

5. Data Element: Psychosocial contraindications (decision data)

Decision: Substance use/abuse is simpler to say (substance use only). Change psychosocial stressors to be plural. Add "or family history" to psychiatric. Take out family history of mental illness. Add "international or undocumented." Add "financial barrier." Add "unable to overcome geographical barriers." Add "unable to identify caregiver support."

Reasoning: Mental illness is too specific. The group added "international or undocumented" due to inability for follow up or logistically unable to do follow up. Also add financial barriers because this is separate.

Next Steps:

Staff will send out the form decisions up to date. The group should be able to get through all of Form B by the end of the next workgroup meeting.

Upcoming Meetings:

- 3/20/2025

Attendance

- **Committee Members**
 - Amy Olsen
 - Annie Doyle
 - Stevan Gonzalez
 - Trysha Galloway
 - Annesha Shetty
 - Jennifer Peattie
 - Kate Dokus
 - Julie Prigoff
 - Tiffany Caza
- **SRTR Representatives**
 - Katie Siegert
- **HRSA Representatives**
 - None
- **UNOS Staff**
 - Sara Rose Wells
 - Emily Ward
 - Lauren Mooney
 - Melissa Gilbert
 - Sam Weiss