OPTN Living Donor Committee Decision Data Workgroup
Meeting Summary
January 16th, 2025
Conference Call

Aneesha Shetty, MD, Chair
Introduction

The OPTN Living Donor Committee Decision Data Workgroup ("Workgroup") met via Cisco WebEx teleconference on 1/16/2025to discuss the following agenda items:

- Living Donor Exclusion Criteria Monitoring Report and Data Request: Malignancy Field
- Continue Review and Discuss Mockup: Form B

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

Announcements

The Subcommittee will meet twice a month in February, March, and April in order to complete the data collection project.

1. Living Donor Exclusion Criteria Monitoring Report and Data Request: Malignancy Field

No decisions were made.

Summary of Presentation:

Staff reviewed the living donor exclusion criteria 2 year monitoring report, which was previously shared with the Committee. One of the policy goals is to expand opportunities for donation for donors with well controlled cancer and well controlled diabetes. The goal of the data collection project is to improve the exclusion criteria. It was difficult to determine history vs. present diabetes. There was a small increase in number of living donors with a history of malignancy, mostly entered under "Other, Specify."

This data request was created to better understand what was entered into "Other, Specify" to determine the data field changes for this subcommittee's project. Free text fields re difficult to analyze. Data from 12/1/2022-12/1/2024 was analyzed. Staff then reviewed the fields in the Living Donor Registration (LDR) form. Some entries into "other" could have been entered into existing fields. Multiple cancers or Cancer (HCC), and skin cancers were the most entered in the "Other, Specify" free text field. Some center used this field much more than others. Some trends could be the result of data imports.

Summary of Discussion

The Chair commented that having the option of more than one choice would be helpful on Form B. When staff at transplant centers try to look for codes, it induces fatigue. It would help if conditions are listed according to organ (fewer options instead of looking thought the entire list).

Another member commented that centers want to provide as much information as possible, but a pop up to review the options carefully and to please pick an already available field would help. Is this patient reported or from centers? It is center reported, filled out by a member of the transplant team.

2. Continue Review and Discuss Mockup: Form B

Please see decisions in the chart below.

Summary of Presentation:

A data management staff member reviewed the mockup from the last subcommittee meeting.

Summary of discussion:

Data Element	Decision	Reasoning/Discussion
History of Malignancy	Yes/No and If yes – add categories. If it is completed on Form B, do not have to fill out form again if the person goes through with donation. Prefer this to be multi select and break this down into organ system. No free text field.	Collected from those who go through with donation and those that do not. It will be collected under medical history and history of malignancy. The Chair commented that any free text makes data analysis difficult. Even if there is explanation, it can't be analyzed. It is unnecessarily burdensome. The group is balancing detail and efficiency. Large volume centers may be able to modify their software to align with the discreet choices and be more successful with reporting. Staff will bring mock up of this field to the next subcommittee meeting
Family history of Kidney Disease Family history of Liver Disease	Yes/No/Unknown Yes/No/Unknown	The subcommittee agrees it should be collected and that the three options are enough. The same question/options should be modeled for Liver candidates, too. Is family history of dialysis needed for donor, as part of history of kidney disease? A lot of inaccurate data may be reported if requesting details. Besides PKD (Polycystic kidney disease), family members often do not know details of kidney disease. One field could be family history of kidney disease/dialysis. The group might want to define family history and what family is included. Centers can define if this is relevant or not.
Family History of Cancer, Coronary Artery Disease, Diabetes	Do not include hypertension, CAD, or diabetes because candidates would not necessarily be ruled out. For cancer, move to Donation Decision Data: Under cancer, add Familial and mutational/genetic cancers	Centers typically ask about diabetes and hypertension. Breeza and NKR Dash are two software tools centers use. The questions developed by this group can align to these systems. Another field is CAD. This is relevant to surgical risk. An echo or stress test can be ordered. The threshold for adding anything should be if it would cause the donor to be declined. A candidate with a family history of diabetes would not necessarily be turned

		down. All three of these are not make or break, but guides decisions. Personal history will outweigh family history for most of these conditions. Should a question about severe mental illness be considered for family history? There has been an increase in living donors committing suicide. The members agreed to phrase this "risk of severe mental illness" can be added to the clinical information. A family history is mental illness will not necessarily rule out a candidate. Family history of cancer can be tied in to the Donor Decision fields. Diabetes, Hypertension, Coronary Artery Disease (CAD) removed per above discussion. Staff asked what specifics would cause a candidate to be declined due to family history of cancer? Familial and mutational/genetic cancers are high risk., especially in first degree family members. This information may be hard to get for those filling out forms. There are some genetic disorders that do not have to do with cancer. This could be a separate category besides family history of cancer. The members decided to move this down to the decision data field.
Genetic disorders	Move to donation decision field, instead of family history.	This may rule out of candidates, but not necessarily.
Donor Decision Data Field	Option to select "Risk of severe mental illness". If someone is ruled out due to mental health, there could then be a drop down that asks about family history. Add Genetic Disorders	This should also be added post donation (mental illness). See above discussion under family history. Genetic disorders was considered as an option under family history, but also would not necessarily rule out a candidate

	Under Cancer, add Familial and mutational/genetic cancers; continue to discuss at the next meeting	
Alcohol Consumption:	Alcohol frequency (liver only) ; Drinks per day Other drug use Cannabis use Smoking Group and change whole category to Substance/Tobacco Use	Agreement to keep all of these, but also a separate category for cannabis use should be added. Staff can share how this is collected at the next meeting. Smoking was added, because use could rule out a category. This category should be grouped and renamed Substance/Tobacco Use

Next Steps:

Subcommittee members should consider questions pertaining to data collection for the Labs portion of Form B for the next meeting. Additional discussion to determine data needed for the Substance/Tobacco Use section will be considered during the next meeting.

Upcoming Meetings:

- 2/6/2025

Attendance

- **Committee Members**
  - Amy Olsen
  - Annie Doyle
  - Aaron Ahearn
  - Katie Dokus
  - Julie Prigoff
  - Stevan Gonzalez
  - Tiffany Caza
  - Trysha Galloway
  - Annesha Shetty
- **SRTR Representatives**
  - Katie Siegert
  - Krista Lentine
- **HRSA Representatives**
  - Adriana Alvarez
- **UNOS Staff**
  - Jamie Panko
  - Sam Weiss
  - Lauren Mooney
  - Sara Langham
  - Laura Schmidt
  - Cole Fox
  - Emily Ward
  - Sara Rose Wells
  - Melissa Gilbert