

OPTN Living Donor Committee Decision Data Workgroup

Meeting Summary

February 6th, 2025

Conference Call

Aneesha Shetty, MD, Chair

Introduction

The OPTN Living Donor Committee Decision Data Workgroup (“Workgroup”) met via Cisco WebEx teleconference on 2/6/2025 to discuss the following agenda items:

- Continue Review and Discuss Mockup: Form B

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

1. Announcements

Workgroup meetings will occur two times a month in February, March, and April. The in person Living Donor Committee meets on April 23rd in Detroit.

2. Continue Review and Discuss Mockup: Form B

Please see the decisions below.

Summary of Presentation:

The substance use category will be discussed at the next meeting when requested information from the last meeting is available. At this meeting, Labs will be considered, as will any additional clinical information needed, and then donor decision data will be considered. As a reminder, the assumption is that as much as Form B, as much as available, should be filled out for candidates who do not go on to donate.

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

Summary of discussion:

Labs

1. Data Element: Serum Creatinine , add estimated GFR (estimate for kidney function) for both kidney and liver
Decision: needed for kidney only
Reasoning: SRTR lists this for kidney only. Donors would likely be disqualified for End Stage Renal Disease but this may be caught elsewhere. For Liver, it would likely be caught at diagnosis, but may be more nuanced for kidney. One member suggested collecting it for liver, but cannot decide why. The group can consider the downside of collecting data, and may be fine if there is a not a large burden on the coordinator and should be easy to find. The group has discussed the possibility of automatic data “dumps” from other systems in the future. Information should be easy to find.
2. Data Element: Measure GFR / Creatinine Clearance (should be combined)
Decision: Combine two (were separately listed), needed for kidney only

Reasoning: Most systems report eGFR

3. Data element: Keep Urine Protein and Urine Albumin, Urine Creatinine Spot (all kidney only)
Decision: Keep spot measurement only, remove 24 hr. data
Reasoning: 24 hour data tends to be inaccurate. Adding a “ratio” for urine protein, there may be a lot variability depending on where a person gets their labs done. The ratio can be calculated if you have all three data points.
4. Revisit blood pressure – should not be in labs
5. Data element: Bilirubin, SGOT/AST, SGOT/ALT, Alkaline Phosphatase, Serum Albumin
Decision: needed for liver only, remove Serum Creatinine (already listed above)
Reasoning: Collecting it for kidney may correlate with substance abuse. It is easy to collect. Will any of these not be available for review? Might be more work than needed for kidney. Remember this is baseline for candidates that don’t donate. Even if easily available, it doesn’t mean it is needed.
6. Data element: Hemoglobin, Platelet Count, White blood cell count
Decision: needed for kidney and liver
Reasoning: Not discussed
7. Data element: INR
Decision: liver only
Reasoning: Not discussed
8. Data element: Liver biopsy data - % macrovesicular fat and % microvesicular fat
Decision: Not needed
Reasoning: Liver biopsies not routinely performed and fat quantification is based on MRI. Also these are imaging questions, not lab questions

Diagnostic Tests

Decision: Whole section not needed because this would be captured will the diagnosis of a condition.

Any additional clinical data

1. Vitals – how much value add is a single reading for blood pressure? Should two values be added? This section may not be needed because it is captured earlier. Listing individuals for paired exchange only asks for one reading. Blood pressure is taken often and tricky. If two separate blood pressure values are captured, what should be used for data purposes? This is also capture under hypertension. IS there concern for hypotension? Not common enough to be significant in this population.

Decision: The group decided the yes/no field under hypertension is enough and a specific measurement is not needed.

Other imaging

1. Must be considered how this will be captured and how much more burden will it cause. Fat quantification and fibrosis scores are needed since in includes thirty percent of excluded liver donors. Modality is not important, but it should be captured. This could just be an estimate. Is this just needed in the donor decision field? There are so many ways to evaluate this and should be a straightforward question.

Decision: Add estimated fat quantification (liver only) as determined by center (add in % in 10% increments until 50, then over 50), add estimated fibrosis stage (liver only) in drop down 0,1, or greater or equal to 2).

Decision Data – why was a particular candidate ruled out? This information is captured here.

1. Data element: question – did the center or the candidate make the decision?
Decision: Remove first question entirely since the second question covers this in detail.
Reasoning: Free text fields are not good for data collection, so they should be minimized. The next question asking for reason covers everything, but with more granular information.
2. Data element: Select the reason for not proceeding with donation
Decision: Keep all the same, except change “Other Living Donor Factor” option to “Another Donor Selected Instead.”
Reasoning: The group also considered recipient related factors, but there is a question about this in detail later on down the form.

As a reminder, if the donor goes on to donate, this Form B is not completed. If a same potential donor does not donate (form closed out) and comes back to donate a year later, they will need to go through the process again. Circumstances may be different. There have been instances in which someone donated a kidney and then came back later to donate a liver. These evaluations are different.

Next Steps:

Additional discussion to determine data needed for the Substance/Tobacco Use section will be considered during the next meeting. The Donation Decision data collection section will also continue to be discussed. Staff will send out the draft Form B up to date, and also the workflow.

Upcoming Meetings:

- 2/20/2025

Attendance

- **Committee Members**
 - Amy Olsen
 - Annie Doyle
 - Aaron Ahearn
 - Katie Dokus
 - Julie Prigoff
 - Stevan Gonzalez
 - Tiffany Caza
 - Trysha Galloway
 - Annesha Shetty
 - Geogry McKenna
 - Jennifer Peattie
 - Michael Chua
 - Reza Saidi
- **SRTR Representatives**
 - Katie Siegert
 - Avery Cook
- **HRSA Representatives**
 - Adriana Alvarez
 - Allison Hutchings
 - Arjun N.
- **UNOS Staff**
 - Sara Langham
 - Laura Schmidt
 - Cole Fox
 - Emily Ward
 - Melissa Gilbert