

OPTN Living Donor Committee
Living Donor Data Collection Workgroup
Meeting Summary
March 17, 2023
Conference Call

Introduction

The OPTN Living Donor Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 03/17/2023 to discuss the following agenda items:

1. Continued review: Living Kidney donor data elements

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

1. Continued review: Living Kidney donor data elements

The Workgroup continued reviewing data elements from the Living Donor Registration (LDR) and Follow-Up (LDF) forms. The Workgroup reviewed clinical kidney specific data during this meeting.

Summary of discussion:

Data element: History of hypertension (LDR)

A member suggested to continue collecting this data element as a binary yes/no as well as collect what types of anti-hypertension medications the individual is on if yes is indicated. A member recommended that the LDR form align with what the SRTR Living Donor Collective collects on hypertension. Another member stated that some transplant programs define hypertension differently and so being less prescriptive about the data definition would be best to which other members concurred.

Data element: Serum creatinine (LDR)

Members agree with how the data is currently collected, stating that adding a date of collection might be helpful to identify when the serum creatinine was measured. Members agreed it is important to collect serum creatinine pre-donation, regardless of whether the date is included or not.

Data element: Preoperative blood pressure systolic/diastolic (LDR)

Feedback thus far questioned whether pre-operative blood pressure was necessary to collect on the LDR, since hypertension data is already being collected. A member agreed that it might be too much to collect both hypertension data and blood pressure data. Another member stated that the burden might be on the coordinators to find the information in the chart. The Workgroup requested more feedback on whether it is necessary to collect preoperative blood pressure.

Data element: Urinalysis (LDR/LDF)

Currently the data field requires entering either the donor's protein-creatinine ration *or* the urine protein. Feedback thus far recommends making it an "*and*" option. Additionally, it was noted that urine protein alone is insufficient clinically. A member stated that this data field should align with what the SRTR Living Donor Collective collects as well as the Kidney Disease: Improving Global Outcomes (KDIGO) recommendations. Another member indicated that their transplant program does not collect urine albumin or albumin creatinine ratios on their living donors currently. Members stated that they do not

have further recommendations at this time due to lack of knowledge on the topic, and requested additional feedback.

Data element: Type of transplant graft (LDR)

Feedback indicated that the response options for en-bloc and dual kidney should be removed as that is not an appropriate option for living donation. Members agreed to remove the dual and en bloc options but did not have further recommendations to make, and requested more feedback, specifically on the hemi-renal response option.

Data element: Intended procedure type (LDR)

Feedback on this data element thus far is that it is important to determine surgery type to consider the potential for complication rates. One member asked if robotic hand assisted surgery would fall under laparoscopic or should a new category be defined. Another member stated that surgical insight might be helpful in this instance and requested additional feedback.

Data element: Conversion from Laparoscopic to Open (LDR)

Members felt that surgical input would be beneficial in deciding whether this question should remain on the form.

Data element: Kidney complications (LDR)

This set of questions only shows up on the form if it was a living kidney donor and would be collected post-operatively, at discharge or six weeks post donation event. Members were asked whether this section can be streamlined or if there is specific data that is relevant to living donor safety that should be collected. Some feedback previously was to combine the vascular complications section with the overall kidney complications section.

One member asked how often vascular and kidney complications are reported as that could inform whether it is necessary to have such a long section. Staff stated that in 2019 there were 12 reported vascular and kidney related complications. Another member asked whether the response options should be more granular for collecting more specific information related to any kind of surgical complications, whether vascular or kidney related. Members agreed that gathering more surgical input on this section would help inform their opinions, and requested additional feedback.

Next steps:

The Workgroup will continue to review OPTN living donor data elements and provide recommendations.

Upcoming Meetings

- April 21, 2023
- May 19, 2023

Attendance

- **Workgroup Members**
 - Angele Lacks
 - Macey Levan
 - Vineeta Kumar
 - Paul MacLennan
 - Stevan Gonzalez
- **HRSA Representatives**
 - Marilyn Levi
- **SRTR Staff**
 - Ajay Israni
- **UNOS Staff**
 - Meghan McDermott
 - Kimberly Uccellini
 - Ruthanne Leishman
 - Carol Covington
 - Samantha Weiss
 - Laura Schmitt
 - Sara Langham
 - Brooke Chenault