

**OPTN Living Donor Committee
Living Donor Data Collection Workgroup
Meeting Summary
December 16, 2022
Conference Call**

Introduction

The OPTN Living Donor Data Collection Workgroup (the Workgroup) met via GoToMeeting teleconference on 12/16/2022 to discuss the following agenda items:

1. Living Donor Feedback Form Review

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

1. Living Donor Feedback Form Review

The Workgroup reviewed data elements on the Living Donor Feedback form.

Summary of discussion:

Living Donor Feedback form

A member suggested the Workgroup consider recommending a modification to the title of the form. Other members agreed that Living Donor Feedback is a confusing title for the intent of the form. Another member suggested the title of the form align with the intent of the form.

Data element: Donor Workup Facility

A member asked whether there is a list of approved transplant programs already provided on the form. Staff confirmed that it is a dropdown menu of approved transplant programs.

An attendee noted that the Scientific Registry of Transplant Recipients (SRTR) Living Donor Collective collects whether the living donor is related to anyone with kidney disease. The Workgroup may consider adding this data element to an OPTN living donor data collection form.

Data elements: Donor last name, first name, middle initial

Members agreed this is necessary information and captured in a straightforward way.

Data element: Donor SSN

Members had no feedback on this data element.

Data element: Donor date of birth

Members had no feedback on this data element.

Data element: Donor race/ethnicity

The Workgroup was informed, that the OPTN is reevaluating how race and ethnicity data are collected, to match the federal government's standards. The question was raised if living donor race and ethnicity data should be collected differently from how it is collected for transplant candidates, recipients, and deceased donors.

An attendee inquired whether ancestry data would be beneficial data collection for living donors. The attendee added that the SRTR Living Donor Collective collects ancestry data. The attendee explained that collection of ancestry data may allow for consideration of genetic differences that can be discovered depending on one's country of origin, and how those differences might or might not relate to risks of living donation. Members agreed on the importance of these considerations. Members suggested discussing this topic with the OPTN Data Advisory Committee (DAC).

Data element: Donor gender

Staff acknowledged that the data collection for gender is not up to date, and that there is potential for the Workgroup to recommend this item to DAC to further consider changes across all OPTN data collection forms.

Data element: Donor ABO

Members had no feedback on this data element.

Data element: Allow OPO to run match

Members had no feedback on this data element.

Data element: Donor histocompatibility

Members had no feedback on this data element.

Data element: Living donor recovery procedure aborted after donor received anesthesia OR living donor organ recovered, but not transplanted?

A member asked if the Living Donor Feedback form is the correct place for this data element. The member explained that the primary purpose of the Living Donor Feedback form is to generate a living donor ID. The member stated this form would be filled out before the information is known to accurately enter this data element. It was noted that “n/a” is the response to select prior to surgery, then the form would be amended to accurately capture the data element once the information is known post-surgery. Members agreed that this is important information to capture, but perhaps altering the placement of the data element and rewording this question is needed for efficiency and clarity.

A member suggested rewording the subsequent fields “*If yes, was organ recovered*” and “*If yes, specify reason aborted*” for clarity. Members suggested that more response options may be needed if more granularity is sought. A member suggested reviewing the open text field for “*other, specify*” to analyze whether there is a common reason that is not listed in the current response options.

Data element: Organ type

A member suggested the OPTN Heart Transplantation Committee provide feedback on whether “*living donor heart transplant*” is needed as a response option. Another member stated that if “*living donor heart transplant*” remains a response option, it should be modified to “*domino heart*”. The member added that the nomenclature across the response options should be consistent.

A member noted that response options related to living vascularized composite allograft (VCA) donor response options need to be added. Staff will follow-up with more information on the implementation of *Modify Data Collection on Living VCA Donors*.¹

¹ OPTN Vascularized Composite Allograft Transplantation Committee, *Briefing Paper*, Modify Data Collection on Living VCA Donors. Public comment period August 4, 2020 – October 1, 2020. Available at <https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/modify-data-collection-on-living-vca-donors/>

Data element: Is the donor participating in any KPD program?

A member suggested to modify this data element so that it is applicable to any paired donation program, not just kidney. Other members agreed. A member noted that the response options would need to be modified to align. Members agreed that the response options should be clarified and simplified.

Next steps:

The Workgroup will continue to discuss the Living Donor Feedback form.

Upcoming Meetings

- January 20, 2023 (teleconference)
- February 17, 2023 (teleconference)

Attendance

- **Workgroup Members**
 - Macey Levan
 - Paul MacLennan
 - Stevan Gonzalez
 - Vineeta Kumar
- **HRSA Representatives**
 - Adriana Martinez
 - Arjun Naik
 - Marilyn Levi
 - Mesmin Germain
 - Jim Bowman
 - Shannon Dunne
- **SRTR Staff**
 - Ajay Israni
 - Bert Kasiske
 - Katie Siegert
- **UNOS Staff**
 - Carol Covington
 - Cole Fox
 - Jen Wainright
 - Kim Uccellini
 - Lauren Motley
 - Lindsay Larkin
 - Meghan McDermott
 - Sam Weiss
 - Stryker-Ann Vosteen
 - Suhan Wang
- **Other Attendees**
 - Carolyn Sidoti