

OPTN Operations & Safety Committee Broader Distribution Data Collection Workgroup Meeting Summary October 20, 2020 Conference Call

Dominic Adorno, Chair

Introduction

The Broader Distribution Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 10/20/2020 to discuss the following agenda items:

- 1. Review and Discussion of Current Data Elements
- 2. Next Steps

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

1. Review and Discussion of Current Data Elements

The Workgroup began reviewing and discussing current data elements related to broader distribution.

Summary of discussion:

Data element: Liver Matching Perfusion

- A member stated that, currently, this is experimental and under clinical trial.
- Members agreed to keep this element as is because of its relevancy for outcomes.
- Members mentioned that there is no calculation needed. Depending on the electronic health record (EHR), it may not be viewable to all and may not be a distinct data collection field.
- Members stated there were no alternative data sources related to this field.

Data element: Type of Liver Machine Perfusion

- A member stated that liver perfusion data elements should be reviewed and discussed once the clinical trials conclude.
- A member stated that data collection related to liver perfusion is important to collect.

Data element: Kidney(s) received on

- A member asked what happens if a kidney is pumped, then put in box and it arrives on ice. The member wondered if this data would be relevant at that time.
- A member stated this data is not difficult to gather and is not ambiguous.
- A member stated that whether kidneys were pumped or not as well as pump time are relevant data elements. The member asked how relevant other pump related data elements were in regards to broader sharing, such as whether a kidney arrived on a pump or not. Staff responded that the total time an organ is on a pump is not currently collected. The member continued by asking whether pump data is also collected on discarded organs in order to have the full picture. Staff responded that pump data is collected on the transplant recipient registration (TRR) form so that data element is only relevant to transplanted organs. Additionally, pump data is collected on the deceased donor registration (DDR) form by the organ procurement organization (OPO), so there is some information but it does not provide a full understanding of what happened to result in the discard of the organ.

Data element: Received on ice

• A member asked if this data is to determine whether, with broader distribution, organs are traveling more often on a pump versus ice.

Data element: Received on pump

- A member inquired about the differences between OPO and transplant program pump practices.
- A member asked if the purpose is to know overall pump time.
- A member mentioned there is a cost element associated with this, in terms of broader sharing practices. The member explained that an individual must stay with the kidney while it's on the pump and must be knowledgeable about what to do if the pump malfunctions.

Data element: Left/Right Kidney final resistance at transplant (if put on pump or stayed on pump)

• A member stated there are no concerns entering this data.

Data element: Left/Right Kidney final flow rate at transplant (if put on pump or stayed on pump)

- A member stated there are no concerns entering this data.
- Staff clarified that this is particular field is collected by the transplant program entered on the TRR and not DonorNet.

Data element: Left/Right: Pump?

• A member asked if this data element is the same as the "received on pump" data element. Staff responded that this is entered by the OPO while the "received on pump" is entered by the transplant program. Staff added that this data is attempting to solidify a sequence of events across the process of transportation.

Data element: Left/Right: Type of Kidney pump/machine

- A member stated this data element seems very straightforward.
- A member stated that most OPOs utilize one type of pump so it would be helpful if it would be programmed in instead of having to enter it for every donor.
- A member asked what the difference in the pumps are besides manufacturer name. Another member responded they perform the same action. A member agreed and does not see the usefulness of this data.

Data element: Left/Right: Specify type of Kidney pump/machine (if other/specify)

- A member stated this data element seems very straightforward.
- A member stated that most OPOs utilize one type of pump so it would be helpful if it would be programmed in instead of having to enter it for every donor.

2. Next Steps

The Workgroup will continue review and discuss data to identify gaps and recommend data element changes.

Upcoming Meeting

- November 17, 2020 (teleconference)
- December 15, 2020 (teleconference)

Attendance

• Workgroup Members

- o Alden Doyle
- o Anna Mello
- Asif Sharfuddin
- o Daniel Stanton
- o Dominic Adorno
- o James Trotter
- o Jillian Wojtowicz
- o Kim Koontz
- o Staci Carter
- Stacy McKean
- Susan Stockemer
- o Susan Weese
- Vandana Khungar

• HRSA Representatives

- o Arjun Naik
- o Raelene Skerda
- UNOS Staff
 - o Joann White
 - o Katrina Gauntt
 - o Kim Uccellini
 - o Kristine Althaus
 - o Lauren Motley
 - Meghan McDermott
 - o Sarah Taranto