OPTN Membership and Professional Standards Committee OPO Performance Monitoring Enhancement Work Group Meeting Summary November 9, 2023 Conference Call

Rick Hasz, Chair

Introduction

The MPSC OPO Performance Monitoring Enhancement Work Group met in open session virtually via Webex on November 9, 2023, to discuss the following agenda items:

- 1. Discuss updated draft OPO referral data collection tool and outcome logic
- 2. Next Steps

The following is a summary of the Work Group's discussions.

1. Discuss Draft OPO Referral Data Collection Tool and Outcome Logic

The Chair reviewed the updated draft organ procurement organization (OPO) referral data collection tool, outcome logic algorithms and examples of reports and measures that are supported by the data capture. The Chair acknowledged that the tool is long because all possible data capture is included and noted that the use of dropdowns and algorithms significantly reduces the data burden. Most OPOs, if not all, are currently collecting this data in some form or fashion. This approach is not just a data collection project; it is requesting that data be collected in a different way. He further noted that his staff complete no more than two screens in a similar tool used by his OPO.

Data:

The Chair reviewed the tool at a high level and noted the purpose for different sections:

- Hospital Information requests information at time of initial referral.
- **Patient Demographic Information** is collected at time of referral. The data of birth is a required field but if unknown at time of initial referral, the age field will appear. The field can be updated once the correct date of birth is known.
- Hospital Referral Process is intended to capture status at time of initial referral, not what happens later in the hospital process. Based on experience, around 90% of referrals are not on a ventilator so the user will respond to the initial question with a "no" and once the user completes the cause of death fields, the record will be closed.
- The rest of the tool is intended to capture data on ventilated referrals with the purpose of understanding the potential for donation.
- Hospital Referral Process captures additional information on response and patient's clinical status at time of referral.
- **Cause/Mechanism/Manner of Death** includes the current OPTN classifications ordered by most frequent. In addition, the tool includes other contributing factors to that cause of death to gather additional information for purposes of risk adjustment.
- Next of Kin (NOK) Authorization Process gathers registry information and information around the approach of the patient's legal next of kin based on the Uniform Anatomical Gift Act (UAGA),

including timing of the donation conversation to try to understand the impact on donation outcomes.

- **Medical Examiner Communication Process** is a high-level capture of whether the patient fell within the medical examiner's jurisdiction and if there was an overall decline for donation. Declines for specific organs are captured later in the tool for actual donors.
- Final Neurological Assessment at Case Disposition is intended to capture whether the patient is a brain dead potential organ donor and if not, capture information on potential for donation after circulatory death (DCD). Some of the information collected in the DCD evaluation is more subjective but will facilitate the start of collection of data around why OPOs may not consider a patient as a DCD candidate. This will help OPOs understand DCD practice patterns and create a better understanding of DCD donation potential.
- **Organ Allocation** will gather information to better understand OPO efforts to place an organ and the reasons why donation did not proceed at the allocation stage of the process or why an individual organ was not allocated.
- **Organ Recovery** gathers additional information on OPO efforts to recover for transplant and importantly, capturing when a potential DCD donor did not die. This will help evaluate the clinical factors that may affect who can be a potential DCD donor.
- **Circumstances of Cardiac Arrest** will be completed if the patient arrested anytime during the process of referral evaluation to understand more about the circumstances of cardiac arrests. Capturing this data can help OPOs work with donor hospitals to affect change and better understand the hospital process and when to communicate about donation.
- **Medical Suitability Evaluation** collects information to help understand when and how medical suitability evaluations are done and to standardize the practice of determining medical suitability. This section collects general donor exclusions and organ exclusions based on organ function. This section includes medical exclusion reasons from OPTN "eligible death" definition, both general and organ specific.
- Classification of Cause of Death for Non-Ventilated Referrals includes a large number of potential causes of death and is data that the Scientific Registry of Transplant Recipients (SRTR) can use for risk adjustment. This list was developed as part of the 2019 AOPO-SRTR Region 8 Pilot Project.

The Chair reviewed examples of outcome logic algorithms for the following organ referral outcomes:

- No Potential for Organ Donation: Not Medically Suitable
- No Potential for Organ Donation: Not Brain Dead, Not a DCD Candidate
- Potential Organ Donor: NOK Decline
- Potential Organ Donor: Patient Arrest
- Potential Organ Donor: ME/Coroner Decline
- Organ Donor

The use of algorithm logic provides flexibility as long as the data captured is defined. The algorithms can be revised to support different reports and measures.

Finally, the Chair reviewed multiple reports that can be populated by the data capture including:

- Total number of referrals
- Total number of ventilated referrals
- Onsite rate for ventilated referrals and for potential donors
- Number of ventilated referrals that were determined to be not medically suitable with number that fall under each reason for unsuitability

• Potential for donation, including numbers for potential donors after brain death (DBD) and potential donation after circulatory death (DCD) donors

- Authorization rate
- Donation rate
- Number of organ donors
- Number of DCD and DBD donors
- Number of organs recovered for transplant
- Numbers that fell within each reason a potential donor may not have moved forward to donation such as next of kin declined, patient arrested, medical examiner declined
- For DCD donors specifically,
 - Number of not DBD referrals
 - Number not considered a DCD candidate and why
 - Number where next of kin was not approached and why including patient arrests where the hospital withdrew support or limited therapies
 - o Recoveries not attempted because patient arrested including where hospital
 - withdrew support or limited therapies
 - Recoveries attempted
 - o Number of recoveries that were attempted but patient did not expire

• Hospital Process Data on referrals for use in giving feedback to donor hospitals which associates authorization rates, conversion rates, potential donor numbers and organ donor numbers with whether the referral was

- Timely and planned
- o Timely only
- o Planned only
- Neither timely or planned

Summary of Discussion:

Decision #1: The Workgroup supported adding death record review to the OPO referral data collection tool.

Decision #2: The Workgroup supported including potential data collection on in-hospital deaths from transplant hospitals in the concept paper.

Decision #3: The Workgroup supported evaluating how the data capture from the tool could be uploaded and populate fields where they occur in the OPTN Computer System and potentially populating fields in the Electronic Donor Records (EDRs) from the OPTN Computer System.

Decision #4: The Workgroup provided feedback on themes for the concept paper.

Decision #1: The Workgroup supported adding death record review to the OPO referral data collection tool.

Based on a suggestion from the SRTR to include missed referrals identified during OPOs' death record reviews, the Workgroup discussed adding a question to the tool and identifying the questions on the tool that would need to be completed during death record review. The Workgroup initially identified that OPO staff would complete parts of the Hospital information, the Patient Demographic Information, Cause/Mechanism/Manner of Death information and potentially the Advanced Directive and NOK Approach by the hospital information. The Chair will review and update the tool to identify the areas that would be completed for missed referrals identified during death record review.

A Workgroup member suggested that a question be added to the tool to identify the method by which the OPO received the referral, electronic, phone call etc.

Decision #2: The Workgroup supported including potential data collection on in-hospital deaths from transplant hospitals in the concept paper.

The Workgroup discussed and supported inclusion of a potential data collection on in-hospital deaths from transplant hospitals in the concept paper. The Workgroup discussed this potential data collection at its August 17 Workgroup meeting. The data collected could provide the ability to validate OPO data and serve as a demonstration project for future data collection from all donor hospitals.

Decision #3: The Workgroup supported evaluating how the data capture from the tool could be uploaded and populate fields where they occur in the OPTN Computer System and potentially populating fields in the Electronic Donor Records (EDRs) from the OPTN Computer System.

The Workgroup discussed ways to decrease the data burden on OPOs by capturing the data once in their EDRs and electronically uploading the data to the OPTN Computer System populating fields on multiple forms within the system. This would avoid the need for OPO staff to enter the same data multiple times. The Workgroup will discuss this further when developing a future data collection proposal. Workgroup members also supported the future development of tools to be made available in the Data Service Portal in the OPTN Computer System.

Decision #4: The Workgroup provided feedback on themes for the concept paper.

The Workgroup suggested that it is important to make it clear that the concept paper is not proposing brand new metrics. The first step is standardizing process and data capture for these earlier phases of the donation process and then develop OPTN data collection. The MPSC cannot even begin to evaluate appropriate metrics until there is sufficient data to support development of metrics. The tool will need to be shared with the EDR vendors. The OPTN will also need to determine a plan for future support and maintenance.

2. Next Steps

The Chair noted that a presentation on the approach and tool would be given to the AOPO Data Committee and at the AOPO meeting the following week.

OPTN Contractor Staff reviewed the high-level proposed concept paper contents. The Workgroup provided feedback on topics to address in the concept paper. The concept paper will be available for review prior to the December 1 Workgroup call. The Workgroup will review the concepts included in the paper and make a recommendation to the MPSC on whether to send the concept paper for Winter 2024 public comment.

Upcoming Meetings

- Workgroup Conference Call, December 1, 2023, 11 am 1 pm ET
- MPSC Conference Call, December 6, 2023, 2 4 pm ET

Attendance

- Work Group Members
 - Richard Hasz, Work Group Chair
 - Kristine Browning
 - o Jamie Bucio
 - o Micah Davis
 - o Chad Ezzel
 - o Kyle Herber
 - o Vicki Hunter
 - o Raymond Lee
 - Scott Lindberg
 - o Paul MacLennan
 - o Deborah McRann
 - o Lori Markham
 - o Malay Shah
 - o Zoe Stewart Lewis
 - o Candy Wells

• HRSA Representatives

- o Jim Bowman
- o Marilyn Levi
- o Adriana Martinez
- o Chris McLaughlin
- o Arjun Naik
- o Daniel Thompson
- SRTR Staff
 - o Jon Miller
 - o Jon Snyder
 - o Bryn Thompson
- UNOS Staff
 - o Sally Aungier
 - o Matt Belton
 - o Robyn DiSalvo
 - o Gabrielle Hibbert
 - o Sevgin Hunt
 - o Krissy Laurie
 - o Eric Messick
 - o Amy Minkler
 - o Heather Neil
 - o Samantha Noreen
 - o Michelle Rabold
 - o Melissa Santos
 - o Laura Schmitt
 - o Sharon Shepherd
 - o Betsy Warnick
 - o Divya Yalgoori
- Other Attendees
 - Dustin Myers, LifeGift Organ Donation Center