OPTN Data Advisory Committee Refusal Codes & Late Turndowns Workgroup Meeting Summary September 16, 2021 Conference Call

Introduction

The Refusal Codes & Late Turndowns Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 9/16/2021 to discuss the following agenda items:

1. Late Turndowns

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

1. Late Turndowns

UNOS staff provided a recap of the project's background and purpose. This effort is to identify how to modify current or add new data collection to provide better information on late turndowns and help inform steps to reduce organ discards.

UNOS staff highlighted the recommendations from previous workgroup calls, which included the following:

Collect the following in "one location"

- Authorization date/time
- Operating room (OR) date/time (not required)
- Enter OR date/time (only required for expedited liver)
- Time of death (DCD and brain death)
- Time of withdrawal (if DCD)
- Recovery date (not always the same as cross clamp)

UNOS staff reviewed the summary and recommendations from the UNOS Research Department's proof of concept presentation. This includes the following:

Summary:

- The "late" in late turndowns depends on when the final refusal occurred.
- We do not have reliable data for when refusals after accepts occur
- If we did have reliable data, we could define late turndowns as: turndowns that occur within a timeframe such that outcomes (e.g. utilization rates) are worse than for organs without any turndowns

Recommendations:

- Require real-time updates for decline after accept
- When the OPO is updating a response, do NOT auto populate the respond date with the previously recorded time
- When the OPO is changing a response from Yes to No, prompt the user to record the following:
 - If this turndown qualifies as a "Late Turndown"
 - If this turndown was 1) pre-operative 2) intraoperative or 3) post cross-clamp

Summary of discussion:

UNOS staff noted that late turndowns can cause issues for both OPOs and transplant programs for a variety of reasons. The OPTN does not currently collect data on late turndowns and there is no clear definition for a late turndown. For example, what would be considered a late turndown when a transplant hospital declines an organ following an acceptance of that organ?

UNOS staff noted that previous workgroup discussions had addressed the issue of schedule OR time and how it can be a moving target for a variety of reasons. The workgroup had previously discussed adding the ability to enter multiple OR times. The OPO Committee supported this as a way to collect multiple OR times just to evaluate how many times it changes or is rescheduled. This could be combined with documenting the reason for the OR time change.

UNOS staff provided an overview of the previous discussions about OPOs entering acceptances in real time. Workgroup members acknowledged that there is variability in practice across OPOs, even though *OPTN Policy 5.6.C: Organ Offer Acceptance Limit* requires OPOs to immediately report organ offer acceptances. UNOS staff noted that organ offer acceptances are pending review of organ anatomy, which can occur in the donor OR. Workgroup members also commented that when an organ is turned down in the OR, the priority is reallocating the organ and not updating the refusals and acceptances in the system.

UNOS staff inquired if OPOs typically document when they receive the notification from the accepting transplant hospital that they will no longer be accepting the organ. OPO representatives on the workgroup responded that OPOs typically document case notes but do not collect the information in a way that it can be pulled from the system. There are not discrete fields within the OPO's electronic donor records.

UNOS staff asked the workgroup members if it would be beneficial to define late turndowns, even if it is a broader definition as a starting point. The Ad Hoc Systems Performance Committee had previously recommended pre-OR timeframes of 0-2 hours, 2-4 hours, and greater than 4 hours. This could help the workgroup determine what data collection is necessary. Additionally, what information is already available that could help define late turndowns and then determine what additional information is needed.

A member suggested that the workgroup step back and evaluate the goal of this effort. The workgroup is trying to determine what data to collect to evaluate the impact of late turndowns but there are numerous moving parts when it comes to placing organs for transplant. The workgroup should evaluate what data is currently being collected, such as match run data, and then determine what additional data would be useful.

UNOS Research staff noted that idea of real time reporting of acceptances was ensuring a more accurate input of a decline after acceptance to identify those change points. Currently it is not reliable data because of responses indicating the same time because the system is auto-populating the previously recorded time. UNOS staff acknowledged that when a decline occurs, data collection is not the first priority for OPO staff. However, from a data driven perspective, it would allow the workgroup to review when the majority of those pre-op turndowns are happening. This information could then inform future discussions around what to do about late turndowns, such as policy proposals around expedited placement.

A member suggested that one approach could be to focus on one organ system at a time. For example, liver has a newly implemented expedited placement system and there are current issues with multiple

acceptances of livers. There has been a monitoring report done for concurrent acceptances and the monitoring report for expedited liver placement is due in November 2021.

A member inquired about the potential for accessing meaningful data from the allocation analysis team. Is there was a way to aggregate and quantify the data from the narratives in the DonorNet donor highlights that could provide additional information. For example, how many hours of cold time resulted due to a late turndown? Was there a late turndown that created the need for the OPO to move to expedited placement? The member again commented that there are numerous moving parts and this might help the workgroup identify the highest priority issue to focus on moving forward.

A member expressed concern about adding more data to the deceased donor registration (DDR) form. There are already over 300 data elements in the DDR and adding more will increase the data burden on OPOs. Another member added that submitting data in the DDR occurs well after the donor recovery and could increase the likelihood of errors.

UNOS staff inquired about the goal of this data collection and ultimately the use of this data. Would understanding the timing and reasons for late turndowns help address a particular problem? For example, if we collect data and determine that 75% of the late turndowns occur within three hours of the scheduled OR, what would we do with that information?

A member inquired about facilitated pancreas allocation and how often it is used. UNOS staff agreed to get the data and bring it back to the workgroup during a future conference call.

Next Steps

UNOS staff reminded the workgroup that the next scheduled conference call on October 21, 2021 from 2:00 to 3:00 pm EDT. UNOS staff will provide information on concurrent organ acceptances and facilitate pancreas allocation. UNOS staff noted that the monitoring report for expedited liver placement would not be available until November/December 2021.

Upcoming Meeting

• October 21, 2021 (Teleconference)

Attendance

• Workgroup Members

- o Jamie Bucio
- o Angele Lacks
- o David Marshman
- o Jennifer Muriett
- o Kristine Browning
- o Sumit Mohan
- o JoAnn Morey
- o Farhan Zafar
- HRSA Representatives
 - o Adriana Martinez
- SRTR Staff
 - o Bert Kasiske
 - o Ajay Israni
- UNOS Staff
 - o Carlos Martinez
 - o Abigail Fox
 - o Isaac Hager
 - Nicole Benjamin
 - o Matt Prentice
 - o Kristine Althaus
 - o Lauren Motley
 - o Lauren Mauk
 - o Lloyd Board
 - o Leah Slife
 - o Susan Tlusty
 - o Robert Hunter
 - o Samantha Noreen