

OPTN Data Advisory Committee Update Non-Use Codes Workgroup Meeting Summary April 20, 2023 Conference Call

Sumit Mohan, MD, MPH, Chair

Introduction

The Update Non-Use Codes Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 04/20/2023 to discuss the following agenda items:

- 1. Project overview and organization activities
- 2. Walk-through the decision tree of potential non-use reasons
- 3. Review existing non-use codes and descriptions for clarity

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

1. Project overview and organization activities

The Workgroup was provided with an overview of the project.

Increasing donor organ utilization is an OPTN strategic goal, and published medical research literature suggests opportunities exist to increase utilization of deceased donor livers and kidneys. Opportunities include clarifying the descriptions available in the OPTN Computer System that are used by organ used by organ procurement organizations (OPOs) to indicate why an organ recovered for transplant was not transplanted. Such organs may be referred to as non-use organs. Because of the importance of increasing organ utilization, the Workgroup's focus is likely a first step in part of a larger comprehensive effort.

Summary of discussion:

The Chair stated the updating the non-use codes may help better understand what is driving non-use of organs and identify the correct solutions to increase organ utilization.

2. Walk-through the decision tree of potential non-use reasons

The Workgroup shared their experiences with determining and entering applicable non-use codes.

Summary of discussion:

A member noted that their OPO staff reviews what happened during allocation and then determines the non-use code that describes the situation. The member stated that transplant programs are better situated to determine why an organ was not utilized than OPOs. The member stated that an OPO would not send out organ offers, if the organ was not appropriate for transplant.

Another member stated that kidneys that are not utilized often result from highly complex donor case. The member stated there are many reasons why an organ ended up not being utilized, so determining and entering one non-use code is difficult. The member noted that the non-use codes do not inform what the impetus was for what ultimately sent an organ down a path towards non-use. The member stated it may be beneficial to collect data on what the first reason was for an organ decline in order to determine what initiates an organ not being transplanted. The member noted that a primary reason that a kidney is not transplanted is due to too much cold ischemic time.

A Workgroup member stated that the reason a donor kidney is declined during the early part of a match run may be different that the reason why it is declined during the latter part of the match run. The member explained that there are many reasons an organ is not transplanted. The member added that since multiple reasons cannot be selected, then "other, specify" or "no recipient located – list exhausted" is usually selected.

The Chair stated that perhaps the OPOs should be allowed the ability to select more than one non-use code. The Chair added that selections could be identified as primary and secondary drivers. The Chair suggested that the Workgroup members should consider updates to the non-use codes that would be actionable. The Chair gave an example of instead of "too old on pump", it may be more actionable data if it was classified as "travel delays". The Chair stated that the more defined the non-use codes can be, the more helpful it will be with future allocation changes and overcoming non-use challenges.

Another member stated it is challenging for OPOs to determine and enter appropriate non-use codes because of the limited options. The member stated there is a disconnect between what a transplant program can identify as a reason for decline and what an OPO can identify as a reason for an organ not being transplanted.

The Chair suggested the Workgroup determine whether the purpose of the non-use codes is to summarize the decline reasons from transplant programs, or if the purpose is something different. The Chair also suggested that the Workgroup analyze whether the last reason an organ was prevented from being transplanted is valuable information to supplement decline codes.

A member stated that reasons for declining an organ vary depending on the where in the process of allocation an organ is. The member stated it will be valuable to understand upstream information of why an organ was ultimately not transplanted. The member suggested that data could capture two events – an initial reason for decline and the final reason for decline. Another member agreed.

The Chair suggested that instead of collecting the initial reason for decline, it may be better to collect why the organ was deemed hard-to-place. The Chair stated that granular non-use codes may help inform OPO best practices and the sharing of best practices between OPOs.

The Chair suggested that the Workgroup consider updating the title of the data field if it is unclear on the intent of the data collection. A member stated that providing definitions for each may be beneficial as well.

Another member noted that they are pursuing older, more complex donors as well as more donation after circulatory death (DCD) donors. The member stated that having granular data on non-use would be beneficial in understanding areas of improvement.

A member stated that the non-use codes do not apply to all organ types.

The Chair requested descriptive analysis of the non-use codes by organ types.

Next steps:

The Workgroup will continue to discuss updating non-use codes.

3. Review existing non-use codes and descriptions for clarity

Summary of discussion:

The Workgroup members reviewed the existing non-use codes and descriptions as part of the walkthrough of the decision tree of non-use reasons.

Next steps:

The Workgroup will review the descriptive analytics of the non-use of donated organs, and use that information to begin identifying opportunities to clarify the code descriptions, as well as continue their discussions of other potential improvements.

Upcoming Meetings

• TBD

Attendance

- Workgroup Members
 - o Sumit Mohan, Data Advisory Committee Chair
 - o Clint Hostetler, OPO Committee
 - o Paul MacLennan, Data Advisory Committee
 - o Bilal Mahmood, Data Advisory Committee
 - o Donna Smith, OPO Committee

• UNOS Staff

- o Lloyd Board
- o Brooke Chenault
- o Nadine Hoffman
- o Sevgin Hunt
- o Robert Hunter
- o Krissy Laurie
- o Lauren Mauk
- o Eric Messick
- o Sharon Shepherd
- o Anne Zehner