OPTN Data Advisory Committee
Refusal Codes & Late Turndowns Workgroup
Meeting Summary
May 20, 2021
Conference Call

Introduction
The Refusal Codes & Late Turndowns Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 5/20/2021 to discuss the following agenda items:

1. Updates
2. Information Technology Programming

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

1. Updates
UNOS staff provided an update on the status of the refusal codes proposal. The Data Advisory Committee voted to submit the proposed list of refusal codes to the Board of Directors for consideration on June 14, 2021. There was one modification to combine “Donor size-height” and “Donor size-weight” as “Organ size-specify (optional).”

2. Information Technology (IT) Programming
UNOS IT staff posed several questions to the workgroup for consideration and to gather feedback.

Summary of discussion:

Numbering Sequence
UNOS IT staff provided an example of how the codes could be numerically labeled. Members recommended adjusting the numbering sequence to allow room for future codes to be added, if needed. The members recommended having each category start with a different ten value (e.g., Donor and Candidate Matching use codes 700-709 and Organ Specific Reasons use codes 710-719).

Comment Boxes
UNOS IT staff presented the list of additional comment boxes proposed by the workgroup. These include:

Organ specific reasons:
- Organ specify, unrequired
- Organ specific test results not available, specify, unrequired
- Unacceptable organ specific test results, specify, required

Donor specific reasons:
- Donor Medical, specify, required
- Graft appearance/quality (VCA ONLY), specify, required
Other:

- Other specify, required

UNOS IT noted that requiring some text boxes and making some optional increases the complexity of the business rules for refusal codes with the “specify” indicator. This additional architecture work will increase the cost and potentially affect the timeline by 2 months due to the additional coding and testing effort. There are various touchpoints affected including potential transplant recipient (PTR) import, web references, stored procedures, and file layouts.

One Workgroup member suggested making all the comment boxes required in order to provide better information. Another member noted that requiring the comment boxes might create a disincentive to use the other codes and could affect the quality of data.

The workgroup ultimately agreed to keep the comment boxes as originally envisioned, with some required and some not required.

UNOS IT staff also sought input on the character limits for the comment boxes. The current limit is 75 and the workgroup members agreed to increase it to 140 characters.

**OPO and Donor Refusal Options**

UNOS IT staff noted that organ procurement organization (OPO) refusal button groups all transplant programs in the donor service area (DSA) and refuses all candidates in one action. Access to this button is available to OPOs as well as the Organ Center. The donor refusal button allows a transplant program to refuse for donor specific reasons for all patients on this match run and future match runs for same or other organs.

UNOS IT staff identified five new codes that need decisions by the workgroup to determine if the functionalities of the buttons described above should be included.

**Candidate temporarily ineligible due to insurance or financial issue**

Workgroup members did not feel this was an issue for OPOs and noted that it should be individual patient based. Therefore, it does not make sense to code out all patients. UNOS staff noted that donor refusal is used across all organs and is based on permissions. For example, if an individual hits the “donor refusal” button it will provide a list of match runs to code out. This also applies the refusal on the current and future match runs. One member commented that it is useful that the donor refusal button’s function applies to future match runs because it would eliminate the need for additional calls if there is a specific donor that the transplant program is not interested in for all organs.

The workgroup recommended not allowing OPO refusal or donor refusal for this code.

**DCD donor neurological function/not expected to arrest**

There was a recommendation to include the donor refusal option for all codes since there is the ability to identify which match runs to apply. This would serve as a valuable tool for efficiency. One member raised a concern about applying this to all patients on the list. For example, a transplant program might refuse for size for certain patients, but not all their patients.

A member recommended allowing all refusal codes to be used when submitting donor refusals across all organs.
Transportation Availability, Donor Family Time Constraint, and Disaster Emergency Management Consideration

UNOS IT staff asked if these three refusal codes would be appropriate options for OPO refusals. One member asked if this means that OPOs refuse on behalf of the transplant program. Another member noted that due to the size of their program’s waitlist, the transplant program established certain criteria that the OPO will use to screen offers automatically. Another member raised concern that this function might be defaulted to a bypass code.

The Workgroup agreed that donor refusals should not be allowed for these three refusal codes in order to avoid creating any unintended consequences.

*New Codes that Need Metadata Alignment*

**Candidate requires different laterality**

The Workgroup agreed this refusal code should be applied to kidney and lung offers.

**Biopsy not available**

The Workgroup agreed to keep this refusal code available for all organs, even though it might be uncommon for heart, lung, and other organs.

**Range Response for Candidate Specific Codes**

The transplant program response, transplant program range response, and range refusals are currently in the system and are not dependent on the refusal code categories. Several questions were presented to the Workgroup, including whether to eliminate range responses or consider broader codes that could apply to a single candidate or range of candidates on the match run.

Members suggested allowing the *Epidemic/Pandemic-Candidate* code to be applied to multiple candidates when submitting a range refusal.

**Donor Specific Reasons**

UNOS IT staff confirmed that based on the previous discussion earlier in the meeting, users will be able to use any refusal code when submitting donor refusals.

**Next steps:**

UNOS staff shared that the internal project kickoff meeting is on May 24, 2021. The timeline for implementation will be discussed based on the decisions made during discussion. UNOS IT requested volunteers to participate in user acceptance testing.

**Upcoming Meeting**

- June 17, 2021
Attendance

- **Workgroup Members**
  - Rachel Patzer
  - Sumit Mohan
  - Anna Mello
  - Jennifer Muriett
  - Kristine Browning
  - Lauren Kearns
  - JoAnn Morey

- **HRSA Representatives**
  - Adriana Martinez

- **SRTR Staff**
  - Nick Salkowski
  - Bert Kasiske

- **UNOS Staff**
  - Emily Kneipp
  - Ben Wolford
  - Kimberly Uccellini
  - Kiana Stewart
  - Lauren Mauk
  - Melissa Lane
  - Nicole Benjamin
  - Robert Hunter
  - Susan Tlusty
  - Samantha Noreen