Transplant Coordinators Committee

Monthly Live Meeting

October 26th

The goal of this Live Meeting was to *pilot test the tool that has been developed by UNOS staff for obtaining the detailed information to be used in improving the documentation found in UNet^{SM}.*

The *UNet^{SM} documentation project* is intended to improve the documentation by:

- clarifying definitions for data elements and making them more specific;
- providing guidance as to possible locations in the patient chart for obtaining the information;
- providing guidance as to how to choose between multiple values in a patient chart; and
- providing examples where appropriate.

This effort was birthed after numerous requests from both the OPTN/UNOS Transplant Coordinators and Transplant Administrators Committees to provide additional guidance regarding the information sought in the fields when completing the data collection forms (e.g. Transplant Recipient Registration form). Three fields were then discussed:

Patient Status Date

The first field discussed was the ***patient status date***. Members discussed the source documentation for this field. One member in Iowa shared that their information is computer-based and another shared that it is contained in the Progress Notes.

The Committee continued discussing when the ***patient status date*** is exactly? Is it at 6 weeks or when the patient is discharged? It was suggested to have a certain week or day after transplant to report this information because people are giving different answers. It was reiterated that the event should be time-based and not event-based - When is it crucial to report it is when it should be documented.

The ***patient status date*** affects a program's outcomes and it was urged that this time be standardized for everyone across the country. Additionally it was reiterated that if we measure how well a patient is doing at a specific time then it will tell us how well or not well the patient will do going forward and tell UNOS and the SRTR more about anticipating outcomes.

Primary Diagnosis at Time of Transplant

This field on the Transplant Recipient Registration form is not collected for Pancreas and for KP, separate diagnoses are collected for these patients. It was asked, how is the ***primary diagnosis*** selected because there could be multiple diagnoses and what source documentation would you use to find the ***primary diagnosis***?

Members shared that they look for the disease that caused the failure of the organ; it is found in the progress notes or in the social medical history.

One member asked if the diagnosis be would what they are listed for and can it be transferred to the form from the waiting list diagnosis.

It was suggested to add a question referring to the number of transplants the patient has received? It was noted that there is information in the system about prior transplants but not collected in the system like other information.

It was strongly encouraged that the ***primary diagnosis*** be what the patient is listed for.

If there are multiple diagnoses, how is the primary one defined? If a liver patient has both Hepatitis C and heptocellularcarcinoma, both are just as important. It was asked what does UNOS want to collect and track and should there be a secondary diagnosis listed?

Diabetes

Members asked how ***Diabetes*** can be clarified on the Transplant Candidate Registration form and what is it <u>exactly</u> that UNOS wants to collect???

It was additionally discussed 1) how these diagnoses are being defined; 2) what are we comparing and why; 3) and how are we going to know that diabetes is defined/described the same way from every transplant center? It was noted that ***Diabetes***, as well as other diseases, labeled as "other or type unknown" gives you a door to do whatever you want with.

Further, Kidney is the only organ where the diagnosis is captured at transplant. It was asked, what if a patient is waiting for a transplant and develops diabetes? How is that information and information if the patient gets diabetes after their transplant, captured on follow-up form?

Committee Feedback

Based on discussions regarding these three fields, members were then asked if the intent of the project is clear; if all the right questions are being asked; and will the tool clarify the information?

Comments include:

- Members want to know first and foremost how people interpret the questions.

- Coordinators are often asked where can I find XYZ information? There are many different people filling these forms out from physicians to data coordinators.

- Are the coordinators finding the information that paints the correct picture of the patient?

- Have clinicians define diabetes and other diagnoses or pass off to the OPTN/UNOS organ-specific committees and / or other groups.

- Begin with elements important with expected survival.

- One misinterpretation is a patient being admitted to the ICU to get lines put in but not needing to be monitored. It was noted that this field was slated for deletion.

- To collect evidence based information, it must be consistent!

- Should start by reviewing factors affecting expected survival because it is significant for transplant.