OPTN Organ Procurement Organization (OPO) Committee
Deceased Donor Registration (DDR) Workgroup
Meeting Summary
November 19, 2019
Conference Call

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Introduction

The DDR Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 11/19/2019 to discuss the following agenda items:

1. Clinical Information Review
2. Next Steps

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

1. Clinical Information Review

The Workgroup reviewed and discussed the clinical information section of the Deceased Donor Registration (DDR) form.

Summary of discussion:

A summary document was created compiling all of the feedback from the Workgroup members on each section of the DDR that was reviewed. Sections that needed further discussion and review were highlighted and reviewed by the Workgroup.

ABO Blood Group

There was agreement among the Workgroup that this is an important data field, and the data element is reliable as it is done with two separate draws and double verification processes. One of the members posed a question of whether or not there is a need to address discrepant results and reverse/forward typing with this review.

A member stated that the intent of this question to address what may improve processes. This information is entered in UNet℠ for allocation purposes and may not be relevant to the DDR. This question may be more appropriate to address in DonorNet®.

UNOS staff stated that this question could be added to a parking lot to address later as it may be more relevant to address in DonorNet®. The Workgroup agreed with this.

Height

The Workgroup agreed that the definition and purpose was acceptable. There was a question on if there was a need to update the help documentation to include guidelines on how to measure double amputees.

The Workgroup Chair stated that if the help document were updated, it would be helpful. UNOS staff stated that this is on the docket to be included in the help documentation and will be addressed in the next quarter.

Weight

There was a question on if there was a need to update the help documentation to specify the weight is "admission weight" because IV fluids, transfusions, and diuresis can affect weight. At what point in time should weight be documented?

The Workgroup Chair stated that admission weight makes the most sense because a weight before organs are allocated is part of the screening. A trauma patient could come in receiving lots of fluids, but this would need to be sorted out during donor management.

A member stated that from a previous Workgroup call, there was discussion regarding organ matching and size. If the purpose of the data element is for organ matching, the definition may need to be narrowed down.

UNOS research staff stated that the definitions should be consistent within the system, especially if being used for screening. The member agreed with this and continued that if the information entered cascades from DonorNet®, it would be important that these definitions are consistent.

Members were also told to think about whether these changes would require a label change because this would need to match uniformly as well. As the Workgroup begins to make recommendations on changes to be made, the work will also include ensuring that DonorNet® and the DDR are in alignment.

Terminal Lab Data

A member asked what the reason would be of having "N/A" or "Not Done" as an option. A Scientific Registry of Transplant Recipients (SRTR) representative stated that these fields are treated as missing data. If these options are encountered, they are inputted during the model building process. If they are used in any of the risk models, these fields are considered as low risk values.

Members were asked to think of how best to define under what circumstances should users select the various options rather than estimating. Would there need to be as many fields of status?

A member stated that an example of this would be if there was a urine protein and the patient is not making urine, would you mark "N/A" or "Not Done"? Essentially, these options mean the same thing.

The SRTR representative asked how this scenario would be reported. If a patient were not making urine, this would seem like it would be a special case that should be captured. It appears that this patient would be higher risk.

A member stated that per OPTN policy, members are required to include a quality note "unable to obtain urine due to anuric" so that if audited, this documentation is available to explain why a urine analysis could not be performed.

Another member asked how urine (protein) was entered in DonorNet®. A member confirmed that the fields are Positive, Negative, and free text below. There are a number of options and it allows for members to document exactly what the lab values are.

The Workgroup recommend that the fields in DonorNet should be used to make the DDR consistent.

Serology

The Workgroup agreed on the importance of the data element. A member commented that labeling the section as "Serology" makes it difficult to determine what tests are performed. It was suggested that the section should instead be labeled "Infectious Disease Testing" and be made into one section that includes the "NAT Results" section.

UNOS research staff stated that the HTLV serology results are not observed as being documented anymore and asked the Workgroup their thoughts on whether this field should be removed.

A member stated that if the field is not required by policy, it should be removed. Additionally, if a particular test is not required, it should not be added to the DDR. The Workgroup agreed with this.

A member stated that in regards to data definition, there is confusion on what the interpretation of serology would be. For an indeterminate serology result, it would be simply indeterminate since it did not make the cut off range.

Another member stated confusion for the "cannot disclose" option. The understanding of this is that historically, there were some states where centers were unable to report HIV results for legal reasons. There is uncertainty on whether this still makes sense to keep this field on the form. UNOS staff will look at the data to determine if this field is still being used.

A member stated that if the testing is from Living Donors, it should not be on the DDR since this form is for deceased donors.

In regards to availability, burden, and interoperability, there is a recommendation to improve the input of these results by having the electronic medical records (EMRs) pushed electronically. A member stated that this should not be prescribed on how it is operated. The Workgroup agreed with this.

NAT Results

There was overall agreement among the Workgroup on the importance of this data element. This particular data element cascades to DonorNet®.

A member voiced confusion on screening results vs. confirmatory results. Another member clarified that this is in regards to the screening aspect for some of the different types of NAT testing. The first run combines Hepatitis B, HIV, and HCV, then break into individual runs for those same tests called confirmatory tests for some definitions.

Another member stated that the only thing that should be reported is the actual result, not the steps leading up to the result. The Workgroup agreed that there should be more clarification on the definitions.

Donor Management

A member stated that this could be improved by "Yes" and "No" questions, as well as the dates and durations of the medications.

Another member asked where these particular medications on the list came from. There are a number of medications on the form that are not commonly used.

A member added that the majority of this data without the aspect of a 24 hour timestamp was already in DonorNet. This information should be cascaded from DonorNet®.

Another member recommended to delete this portion of the DDR. This information is already being documented more clinically and the fields in the DDR are more of a summary of that data.

UNOS staff stated that this may entail research and consultation with subject matter expert (SME) Committees to determine if there is a need for this section of the DDR. This section would tie into the development of a process for deleting data elements from the DDR. This includes making sure that the

deletion of these data elements will not interfere with data from an SRTR standpoint and organ specific data. This will be the first entry into the possible deletion pathway. The Workgroup agreed with this.

Next steps:

The Workgroup will continue to review the Clinical Information section of the DDR and will also discuss the Lifestyle Factors section during the next Workgroup meeting.

The meeting was adjourned.

Upcoming Meeting

- December 17, 2019