

**OPTN Organ Procurement Organization (OPO) Committee
Deceased Donor Registration (DDR) Workgroup
Meeting Minutes
December 17, 2019
Conference Call**

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Introduction

The DDR Review Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 12/17/2019 to discuss the following agenda items:

1. Clinical Information Review
2. Lifestyle Factors Review
3. 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:

The Workgroup reviewed the highlights from the last conference call meeting. A member suggested deleting the list of medications in the Donor Management section. This information is already being collected and most Organ Procurement Organizations (OPOs) attached this information in DonorNet® from their electronic medical record (EMR).

UNOS research staff stated that the only limitation to this would be if there was something needed for risk adjustment. It may be that DonorNet® has the information that is needed for this. It is unknown how SRTR uses these particular data elements currently, but this could be looked into further.

A member stated that in an effort to decrease discards and better understand donor management and how this influences outcomes, removing the medication list completely would not make sense.

Another member stated that the current state of the medication list is not effective as it is too vague. A solution to this would be having the ability for OPOs to upload the medication lists from EMR.

UNOS staff will create a number of pathways for data elements that need further clarification and discussion. The Workgroup decided to categorize the medication list as possible deletion or revision.

The Workgroup continued their review of the DDR data fields. Sections that needed further discussion and review were highlighted and reviewed by the Workgroup.

Inotropic Medications at Time of Cross Clamp

There were some concerns raised on the reliability of this data element, as there are variations in how this information is documented. The Workgroup discussed possible ways that this information could be improved. The Workgroup Chair suggested modifying the help documentation to make it clearer. Cross

clamp can be challenging to record and it seems reasonable to record this at a certain period of time (ex., within 15 minutes of cross clamp).

A member stated that the question is trying to measure hemodynamic instability at that point in time. A slightly longer window makes sense to capture this data accurately and still provide information that is needed.

Another member stated that typically these medications are taken off at the time of withdraw. It is unsure what this means in the context of Donation after Circulatory Death (DCD) donors. A member suggested that the definition of DCD be revised. The Workgroup Chair agreed with this and suggested that this be part of the help documentation. It was recommended that the language for DCD and brain death should be separated.

A member suggested using the time for cardiac standstill. There probably will not be cardiac standstill on a DCD, but it would be a little more consistent in showing what medications were being administered at the point when the heart stopped circulating.

UNOS staff suggested that if time of cross clamp is not the best timeframe to collect the data and information we are trying to capture, there could be discussion around what the best timeframe would be.

The Workgroup determined that further review and modification would be needed for this section.

Number of Transfusions during Terminal Hospitalization

The Workgroup Chair stated that it might be hard to determine the amount of blood that is used. A member stated that there is variation in this, especially among pediatric patients. Instead of the number of transfusions, where the volume can vary, it would be more precise to document the exact amount of blood used.

The Workgroup Chair continued that it would be helpful to know how the data is being utilized as well and how this information is being entered in DonorNet.

The Workgroup determined that further review and modification would be needed for this section.

Clinical Infection Confirmed by Culture

The Workgroup agreed that this data was important but there was uncertainty of how this information is being used.

A member stated that in the past, there was an initiative looking into members being able to share culture results more effectively. This would be a great template in capturing this information. UNOS IT staff clarified that the initiative described is the project addressing the reporting of post-recovery test results that is currently being programmed. UNOS IT staff agreed to share a mockup of this data collection will be shared with the Workgroup as the project develops.

The Workgroup Chair stated that this question is very broad and that clarification of this section would be needed. It appears that there are many changes made to this field, and it is probably because members are entering the final cultures, which makes it seem that this is not collecting good data.

The Workgroup Chair suggested reaching out to the OPTN Ad Hoc Disease Transmission Advisory Committee (DTAC) for feedback on this section to help in determining any additional information that may be needed. The Workgroup agreed with this.

2. Lifestyle Factors Review

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

Summary of discussion:

The Workgroup reviewed highlighted comments from the Lifestyle Factors section of the DDR.

Cigarette Use (> 20 pack years) – Ever

A member stated that this data element is well established in healthcare and is standard; however, it might not provide the information you would want to know about a potential donor.

SRTR staff stated that 20 pack years is a well-defined threshold, as there is a lot of clinical validity. It depends on what data needs to be collected – this could also be measured by asking for an actual value, but pack year should be a part of this data collection.

SRTR staff asked the Workgroup members how easy this information is for OPO personnel to collect. It is a well-designed construct in epidemiology. There is support in keeping this data field if it is easy for the OPOs to collect this information.

UNOS staff asked if there was a more objective clinical measure that would be easier to obtain. SRTR staff stated the pack year threshold is standard and is how it is documented in the EMR. If smoking history is available, invariably it is measured in pack years. The only other measure that is recorded at times is when distinguishing a never smoker from a pure risk standpoint, which is 100 cigarettes total in an individual's lifetime. This data would be harder to capture.

UNOS research staff asked if vaping history should also be collected. SRTR staff stated that this has been discussed, and because vaping is becoming more prevalent among younger patients and individuals, this is moving towards becoming a required data field in the EMR.

SRTR staff stated that this would be a good opportunity in getting ahead to collect this data. Right now, vaping history is being captured as Yes or No. This information would bring a lot of value, particularly for the lung transplant community.

A member stated that there should be consideration in how best to phrase this question to capture the intended information. For example, if an individual is a cigarette smoker and then switches to vaping, how should this be asked in order to capture this information accurately?

Cigarette use continued in last six months

The Workgroup was asked if the way of collecting this data makes sense and if fields asking if continued usage in last six months should be collected. A member stated that this depends on how this is currently being collected. It is not believed that this information is being collected routinely.

The Workgroup Chair stated that the pack use history and then this section should be used. The question would be if the historian (person reporting this information) is a reliable source.

SRTR staff stated that in some modeling, having this history is important and helps in modeling.

The Workgroup recommended keeping these sections on the DDR.

Cocaine Use – Ever

The Workgroup Chair stated that the terms “abuse” and “dependency” would need a clearer definition. A member stated that capturing frequency would be great, but this would be subjective as the data would be based on how the historian feels about the individual's drug use.

The Workgroup Chair suggested in modifying the question to “ever use” rather than “abuse” or “dependency”. The Workgroup reviewed the data definition form where it is defined as the donor having ever abused or had a dependency to cocaine.

A member stated that it would be better to review the origin of this question and be more specific and precise in what needs to be collected. Another member stated this information should mirror the information that is already being collected in the EMR. Questions such as what drug was used, what was the duration, and what was the route the drug was administered would be helpful.

The Workgroup decided to send this data element to the organ-specific Committees to determine who is specifically using this data and for what purpose.

An SRTR staff stated that even if the data element is not being currently used, it is important to have this in the dataset to understand what impact, if any, this has. They also noted that to make the data more meaningful and useful, it would be best to better define what needs to be collected.

A member stated that this information is being collected in a very robust way at the OPO level but then they have to fit that information into the categories within the DDR.

The Workgroup agreed that this section would need additional discussion and review.

Heavy Alcohol Use (Heavy = 2+ drinks/day)

The Workgroup agreed that this data element is important to help evaluate organ function.

The Workgroup Chair stated that it is uncertain if this information is used differently if the individual is male versus female.

The OPO Committee had discussed this previously and had determined that there would need to be clarity on what this information is trying to capture.

The Workgroup decided to consult with the Liver Committee to get their feedback on the best way to collect this information and define the question.

Next Steps

The Workgroup will continue to review Lifestyle Factors section of the DDR. The Workgroup members will be assigned additional sections to review and provide feedback.

The meeting was adjourned.

Upcoming Meeting(s)

- TBD