OPTN Organ Procurement Organization (OPO) Committee
Deceased Donor Registration (DDR) Review Workgroup
Meeting Minutes
August 27, 2019
Teleconference

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Introduction

The Deceased Donor Registration (DDR) Review Workgroup met via teleconference on August 27, 2019 to discuss the following agenda items:

1. Overview: OPTN Data Element Standard of Review
2. DDR Review
3. Next Steps

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

1. Overview: OPTN Data Element Standard of Review

UNOS staff provided the Workgroup with an overview of the OPTN Data Element Standard process.

Summary of discussion:

UNOS staff began by explaining that the OPTN Data Element Standard process is intended to standardize how Committees review and propose changes to OPTN forms. UNOS staff is collaborating with the UNOS Organizational Excellence team to develop a process for the Workgroup to evaluate. The process presented to the workgroup will be something that would be used for all future Committee projects. The overall goal of this project is to evaluate and improve the quality of data.

The tool (checklist) developed is a table of questions for any Committee to use that would help in the evaluation of data and changes they plan to propose. The review is intended to evaluate whether data collection will align with the OPTN Data Vision Statement and OPTN Data Collection Principles.

UNOS staff provided workgroup members with definitions for each standard within the data evaluation tool:

- Purpose: Begin collecting the intent of the data element within the appropriate definitions and ensuring that the collection of the data is logical and will be valuable.
- Relevancy: Determining if the data is meaningful to the performance of the process or application for which they are collected. From the perspective of the OPTN, this would pertain to whether the data is still relevant in the context of the current donation environment.
- Face Validity: Assessing whether the data measures what was intended to measure.
- Reliability: Refers to consistency in the extent to which data are producible or reproducible.
- Definition: Ensuring that the defined data elements are being used universally.

UNOS staff explained that behind all data elements on OPTN forms, there is help documentation that provides a description of each field and what specific information is needed for each field. Moving forward under the new process and new OMB requirements, this process would be worked on much earlier than it had in the past.

- Availability, Burden, and Interoperability
  - Availability: The ability of a user to access required information when needed.
  - Burden: The time, effort, or resources that would be required of members to collect the proposed information. As a part of the OMB process, a burden assessment is required.
  - Interoperability: The ability of different information systems, devices, or applications to connect in a coordinated manner within and across organizational boundaries to access, exchange, and cooperatively use data among stakeholders with the goal of optimizing the help of individuals and populations.
- Alternative Data Sources: To mitigate members entering the same data more than once by determining if a particular data element is already available via an external source. The intent is to avoid having to report the same data to multiple sources.
- Usability and Conformity: Does the form make sense to the users, does the organization of the fields on the form make sense, and is the form user friendly?
- Implication of Removing Data Element: Assessing if the removal of a data element impacts other information to ensure that the collaboration is done well in advance before any fields are removed.

UNOS staff summarized that the tool is part of a process. This Workgroup is the first to use the tool and have been asked to evaluate and provide feedback with the thought that this tool would be used among other Committees for further data review projects.

The Workgroup Chair asked how the Committee would know who is using the data in other places. UNOS staff noted that this would be staff responsibility to research and provide this information to the Workgroup.

2. DDR Review

UNOS staff reviewed a proposed checklist in reviewing the DDR among the Workgroup.

Summary of discussion:

UNOS staff drafted a checklist based on the OPTN Data Element Standard of Review process. The Workgroup members were asked to provide feedback on the best approach for collecting feedback. The Workgroup will have the ability to revise and edit the checklist to ensure that it is user friendly not only for this project but also for future Committee work.

The Workgroup Chair asked that when filling out the checklist and putting in an opinion for each data element, how will a conclusion be made on a final decision. UNOS staff explained that each member will be assigned a few data elements to review and provide feedback. The feedback will be sent to UNOS staff to compile and would be discussed during the monthly Workgroup calls to make a final decision at that point. The Workgroup Chair asked for clarification that the Workgroup is not focusing on changing anything with policy but instead just the data points. UNOS staff confirmed that this was correct.

A member suggested that it would be helpful to have the checklist in a shared document so that other members would be able to access and see what feedback is being received. UNOS staff stated that SharePoint would allow for the checklist to be shared and added that there can be some collaboration done through this tool.

UNOS staff stated that the advantage of providing individual feedback is that it allows everyone to evaluate the data elements on their own and to come together as a group to determine if the general responses were consistent or if there is variation.

Another member asked for clarification on the type of answers the Workgroup members were expected to provide. UNOS staff explained that the feedback would entail going through each data element and answering the questions based on the prompts that were just reviewed for each standard. A separate document will be provided to Workgroup members that highlight the standards and their definitions to help guide Workgroup members when evaluating each data element. If there are prompts that do not make sense, Workgroup members were asked to provide feedback or label them as not applicable (N/A).

The Workgroup Chair suggested that as most of the Workgroup members may be more familiar with the clinical information section of the form, it may be easier to begin the evaluation there.

3. Next Steps

Summary of discussion:

UNOS staff proposed that Workgroup members use the checklist and provide feedback on a few data elements in order to test the process. This can then be discussed during the next Workgroup's call and adjustment can be made, if needed. The Workgroup members were in agreement with these next steps.

The Workgroup Chair stated that for the fields that are required can be reviewed and discussed but asked for clarification that if a specific field is required and it was decided that there should be a modification to that field, it would require a policy change.

UNOS staff clarified that anything with a policy implication can be put on a backlog. The Workgroup can make the appropriate referral to the respective Committee for further evaluation. Any potential policy changes that are discovered during the evaluation would be separate from this project. UNOS staff added when reviewing organ specific clinical information, there may be a need to consult with the appropriate organ specific committee. This can be determined as the project progresses.

The Workgroup Chair asked if there was any information in regards to following up on fields that automatically upload to DonorNet. UNOS staff stated that there was some information on the DonorNet fields that cascade to the DDR, but further review is needed before presenting it to the workgroup.

Next Steps:

- UNOS Staff will send Workgroup members the checklist for further review.
- Workgroup members will test the worksheet using the clinical information section of the DDR.

Upcoming Meeting

- September 17, 2019