

**Data Advisory Committee
Meeting Minutes
April 22, 2019
Conference Call**

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Introduction

The Data Advisory Committee (DAC) met via Citrix GoToTraining teleconference 04/22/2019 to discuss the following agenda items:

1. Summary of previous week's activities
2. Review contents of Transplant Information Electronic Data Interchange (TIEDI) forms

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

1. Summary of the previous week's activities

DAC reviewed the discussion and decisions made during the last Committee conference call.

Summary of discussion:

Previously, the DAC had agreed that it is a legitimate action to prevent data changes to submitted data following an appropriate length of time. They also decided that data elements should be locked at some point following members' submission and validation and changes could be permitted with a required explanation.

UNOS staff summarized for the Committee the presentation made to the OPO Committee on April 16, 2019, and that Committee's subsequent feedback. UNOS staff reported that the Organ Procurement Organization (OPO) Committee supported the elimination of OPTN Policy 18.4: *Data Submission Standard*. Some OPO members also stated that the 30 day timeframe for submitting the Deceased Donor Registration (DDR) form is too restrictive for their organization to perform both the data entry and the data quality review adequately. As a result, OPO members said they submit the requested data by the timeframe, and then make changes afterwards.

The OPO Committee also reported that they would be launching an evaluation project analyzing the Deceased Donor Registration (DDR). A DAC member asked for data on the frequency at which OPOs are modifying entered data. OPTN staff reported that 13% of DDR forms validated in 2017 had been modified after their initial validation date. Another Committee member commented that the rate at which erroneous data is submitted should be examined further.

Another Committee member suggested giving OPOs more time to submit data before it is locked. For example, the DAC should decide if the submission of data and the locking of data should be one and the same or two separate timeframes. A member who is more familiar with OPOs suggested a two-step process in which OPOs will have the opportunity to add or update data within a certain timeframe. This Committee member also reported that a shorter timeframe for initial submission should be adequate.

2. Review contents of TIEDI forms

UNOS staff reviewed the multiple reasons why data may need to be changed after initial submission and then presented the types of data collected on the DDR.

Summary of discussion:

UNOS staff presented the submission timeline options and asked the Committee which options they felt would be most appropriate when applying a data lock to the DDR. A Committee member responded that this policy change should be aimed at modifying behavior and questioned how much time the Committee should spend on data analysis when compared to the data and sentiment DAC could gather during a public comment process. Another Committee member responded that they believed that more should be done with data that exists on the front end when dealing with policy development. This member also reported that merely asking the community what they thought may lead to little or no change.

Another Committee member commented that the timing for the slowest arriving pieces of information should serve as a basis for when data is to be locked. This Committee member suggested looking to the 2017 data for patterns and trends as this could inform DAC as to which information takes longer to obtain. For example, lab cultures may require up to 14 days for results to return to OPOs. Furthermore, misinterpretation of tests can lead to inaccurate entry, thereby reinforcing the need for a data to be unlocked.

A Committee member suggested creating a system whereby a report is produced between the time data is submitted and locked. Such a report could alert users of data that is inaccurate. Furthermore, a few Committee members preferred a larger amount of time between data submission and locking in order to reduce the number of unlock requests in the future.

Another Committee member suggested that a timeframe of 30/90 days could be a reasonable data lock. Essentially, this would mean that at 30 days the data would be initially required and then 90 days after the initial date, the data would be locked (e.g. for an official due date of 120 days after the event occurs).

A Committee member commented that there should be clarification in policy language regarding the verbiage “due” will mean. Another member said that there should be a separation of the initial submission due date and quality review due date, along with an exact definition for each in order to avoid any misinterpretation or confusion.

Next steps:

The DAC will continue to develop recommendations for data locks.

Upcoming Meeting

- April, 29