Modify Data Submission Policies

*OPTN Data Advisory Committee*
What problem will this proposal address?

- Concerns about quality of data reported to the OPTN resulting from:
  - Unclear data submission deadlines
  - Data changes made after submission
- Questions about accuracy of data used by members and researchers for performance evaluations
- Improve confidence of research findings and organ allocation
- Growing recognition of OPTN data quality needs
  - DAC now an operating committee under Board of Directors
  - Requires annual report
Proposal Affects TIE-DI Records

<table>
<thead>
<tr>
<th>Form Name</th>
<th>Acronym</th>
<th>Member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deceased Donor Registration</td>
<td>DDR*</td>
<td>OPO</td>
</tr>
<tr>
<td>Donor Histocompatibility</td>
<td>DHS*</td>
<td>Histocompatibility Lab</td>
</tr>
<tr>
<td>Recipient Histocompatibility</td>
<td>RHS*</td>
<td>Histocompatibility Lab</td>
</tr>
<tr>
<td>Living Donor Registration</td>
<td>LDR*</td>
<td>Transplant Hospital</td>
</tr>
<tr>
<td>Transplant Candidate Registration</td>
<td>TCR*</td>
<td>Transplant Hospital</td>
</tr>
<tr>
<td>Transplant Recipient Registration</td>
<td>TRR*</td>
<td>Transplant Hospital</td>
</tr>
<tr>
<td>Transplant Recipient Follow-up</td>
<td>TRF</td>
<td>Transplant Hospital</td>
</tr>
<tr>
<td>Living Donor Follow-up</td>
<td>LDF</td>
<td>Transplant Hospital</td>
</tr>
</tbody>
</table>

*Denotes events where all data are likely to be available when form is due
Substantial proportion of data not submitted by due date

Due date requirements:
30 days: DDR, DHS, RHS, TCR, TRF
60 days: TRR, LDR, LDF

% of Submitted TIEDI forms (2018 Q4)

% submitted as of due date
% of forms submitted within 90 days of due date
Many TIEDI forms are changed after due date, such as TRR

TRR Example

- TRR due date: 60 days after transplant hospital removes recipient from waiting list
- Includes different types of data modifications, such as filling missing values or changes in actual values

Number of days from due date to final form modification

# of Submitted TRR Forms (2017) = 34,743

44% of forms were changed after due date

- 56% Before or on due date
- 13% Within 30 days
- 4% 31-60 days
- 4% 61-90 days
- 24% More than 90 days
Proposed Solution: Extending and Clarifying TIEDI Data Submission Deadlines

<table>
<thead>
<tr>
<th>Form</th>
<th>TIEidi data submission deadlines (number of days)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Current policy</td>
</tr>
<tr>
<td>DDR</td>
<td>30</td>
</tr>
<tr>
<td>DHS</td>
<td>30</td>
</tr>
<tr>
<td>RHS</td>
<td>30</td>
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<tr>
<td>LDR</td>
<td>60</td>
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<td>TCR</td>
<td>30</td>
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<tr>
<td>TRR</td>
<td>60</td>
</tr>
<tr>
<td>LDF</td>
<td>60</td>
</tr>
<tr>
<td>TRF</td>
<td>30</td>
</tr>
</tbody>
</table>
Proposed Solution – Data “Lock”

- Data considered final on due dates in Policy 18.1 and no longer editable
- Implement a process for changing final, “locked” data
  - Must take an action to unlock data
  - Indicate why data are changing
  - Provide name of approver in leadership position from member institution
- DAC summarizes data completeness and changes to Board of Directors on periodic basis
Proposed Solution: Enhance Member Resources

- Improve reporting resources to assist with quality review
  - Enhance current data quality tools to address need to identify issues in TIEDI collection instruments before being “locked”
  - Help members identify data outside normal ranges before they submit

- Implement data quality dashboard
  - Create visual tool for members to compare their data with nationally reported data
  - Provide member reporting about frequency and reasons for data changes
How will members implement this proposal?

- Transplant Hospitals, OPOs, and Histocompatibility Labs
  - Data “lock” will require members to comprehensively review data collection, entry, and validation practices to optimize data accuracy and completeness by the submission deadline
  - “Unlocking” and changing data will require a rationale and organizational leadership approval
  - Adjust data practices to comply with new requirements
How will the OPTN implement this proposal?

- Requires programming in UNet<sup>SM</sup>
- Enhance and create additional member tools in Data Services Portal
How will the proposed change be evaluated?

- Committee will report at least annually to Board of Directors
  - Data submission compliance rates
  - Frequency of data changes
  - Reported reasons for data changes
Feedback Requested

- What are the most common reasons your organization changes TIEDI-specific data after submission?
- What are the most common factors preventing your organization from submitting accurate data within the established timeframes?
- What tools would help your organization (a) submit data on time, and (b) quickly identify data discrepancies?