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 TIEDI Records

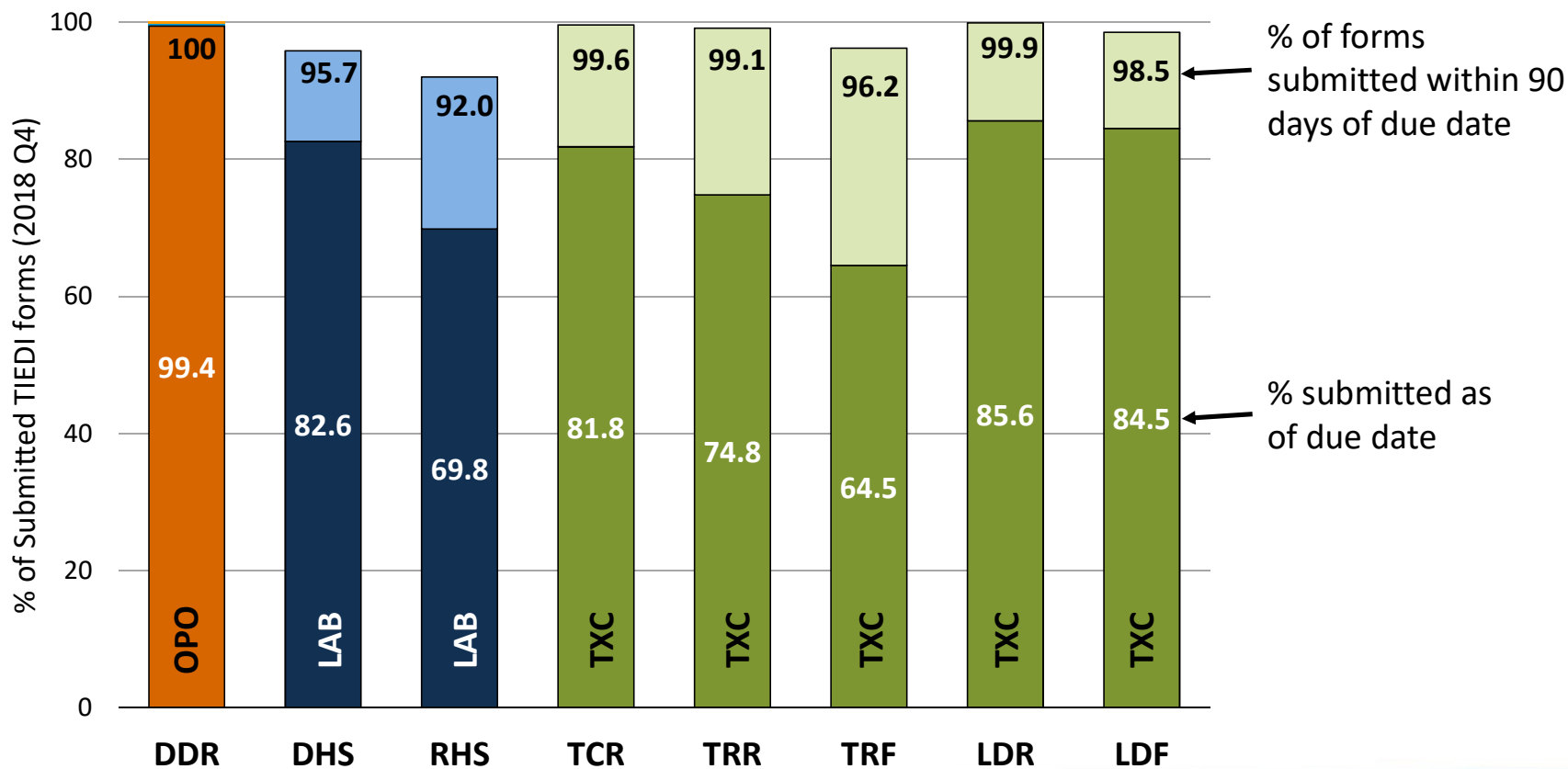| Form Name	Acronym	Member
Deceased Donor Registration	DDR*	OPO
Donor Histocompatibility	DHS*	Histocompatibility Lab
Recipient Histocompatibility	RHS*	Histocompatibility Lab
Living Donor Registration	LDR*	Transplant Hospital
Transplant Candidate Registration	TCR*	Transplant Hospital
Transplant Recipient Registration	TRR*	Transplant Hospital
Transplant Recipient Follow-up	TRF	Transplant Hospital
Living Donor Follow-up	LDF	Transplant Hospital

*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:
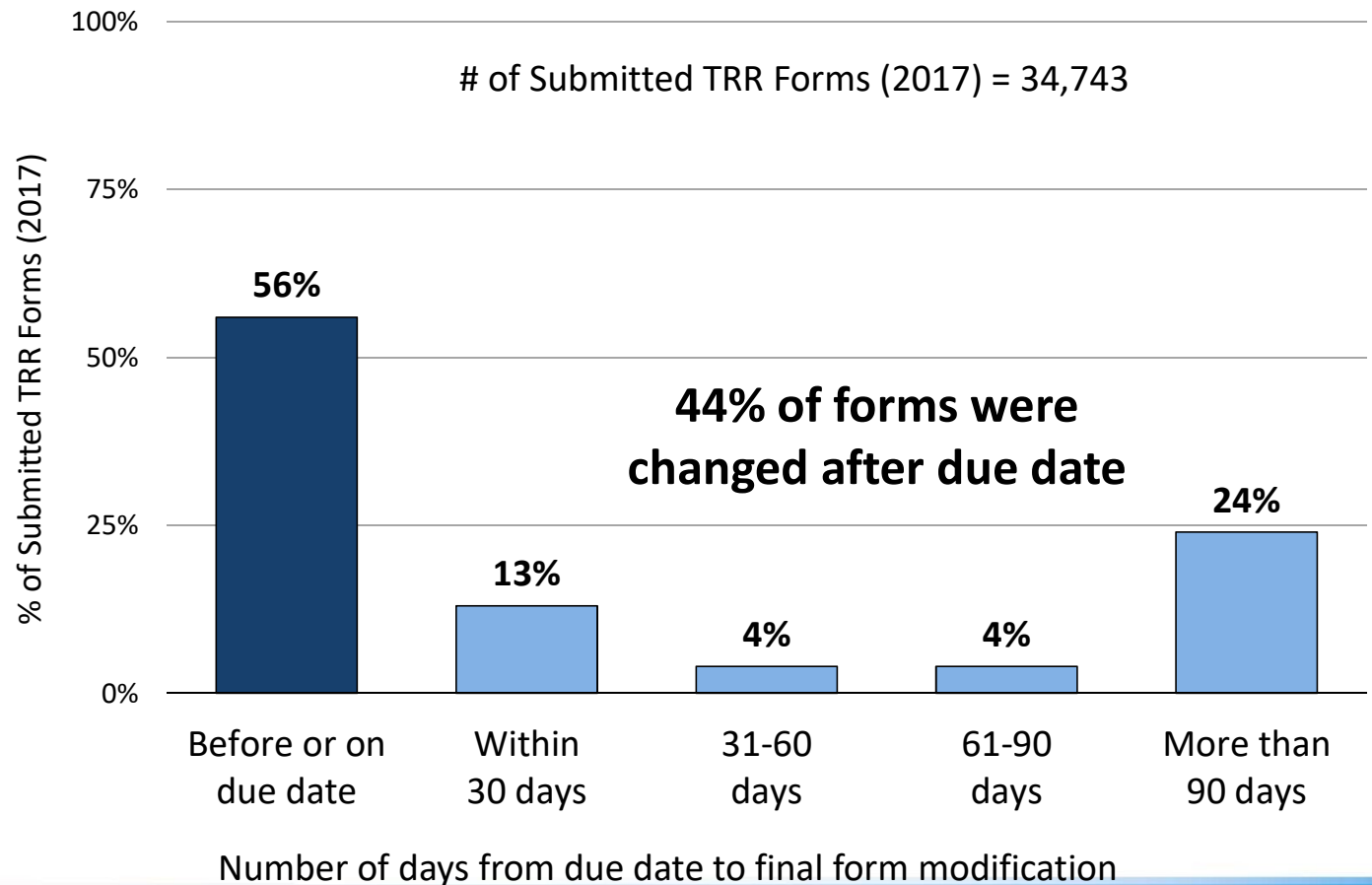
<u>30 days:</u>
DDR, DHS, RHS, TCR, TRF

<u>60 days:</u>
TRR, LDR, LDF

% of Submitted TIEDI forms (2018 Q4)

DDR	DHS	RHS	TCR	TRR	TRF	LDR	LDF
100	95.7	92.0	99.6	99.1	96.2	99.9	98.5
99.4	82.6	69.8	81.8	74.8	64.5	85.6	84.5
OPO	LAB	LAB	TXC	TXC	TXC	TXC	TXC

% of forms submitted within 90 days of due date

% submitted as 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

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

44% of forms were changed after due date

Before or on due date	56%
Within 30 days	13%
31-60 days	4%
61-90 days	4%
More than 90 days	24%

% of Submitted TRR Forms (2017)

Number of days from due date to final form modification

Proposed Solution: Extending and Clarifying TIEDI Data Submission Deadlines

TIEDI data submission deadlines (number of days)			
Form	Current policy	Proposed policy	Change
DDR	30	60	**+30**
DHS	30	60	**+30**
RHS	30	60	**+30**
LDR	60	90	**+30**
TCR	30	90	**+60**
TRR	60	90	**+30**
LDF	60	90	**+30**
TRF	30	90	**+60**

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^{SM}

- 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?