OPTN Data Reporting in Era of COVID

Virtual Transplant Quality Institute October 6, 2020

Sarah Taranto Principal Data Analyst, UNOS Research Department

Acknowledgement

This work was supported wholly or in part by **Health Resources** and **Services Administration (HRSA)** contract 250-2019-0001C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

Objectives

Review changes to OPTN data collection and submission requirements in response to COVID-19 pandemic.

Review upcoming changes to TIEIDI data submission requirements - the "Data Lock".

Demonstrate new tools available to assist all OPTN members with improving TIEDI data submission timeliness and accuracy.

COVID-19 Related Data Submission Changes

Policy Changes

- Updates to candidate lab data
- Modifications to wait time initiation for non-dialysis kidney candidates
- Relaxation of TIEDI TRF/LDF/PTM data submission and living donor follow-up requirements (amnesty)

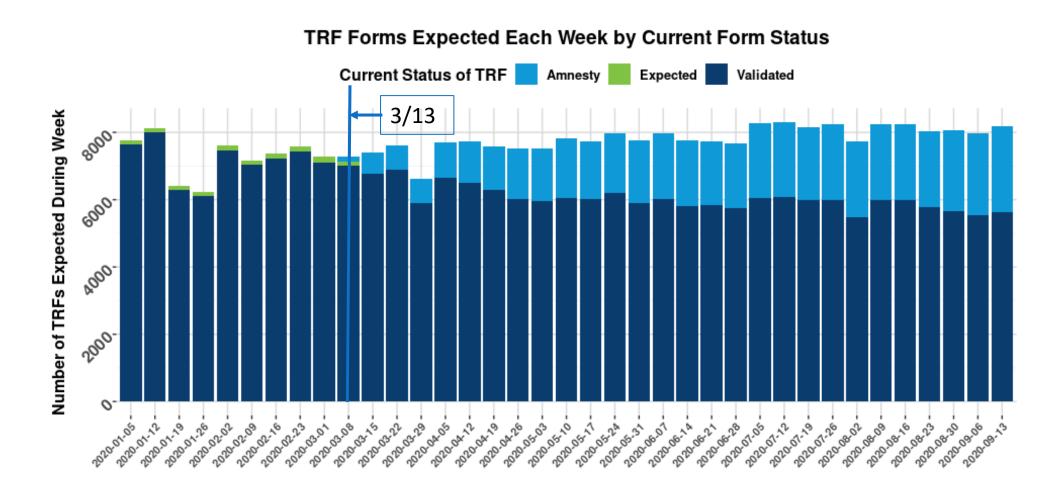
System Changes

- Addition of organ refusal reasons
- Addition of new causes of death
- Addition of COVID-19 donor testing results

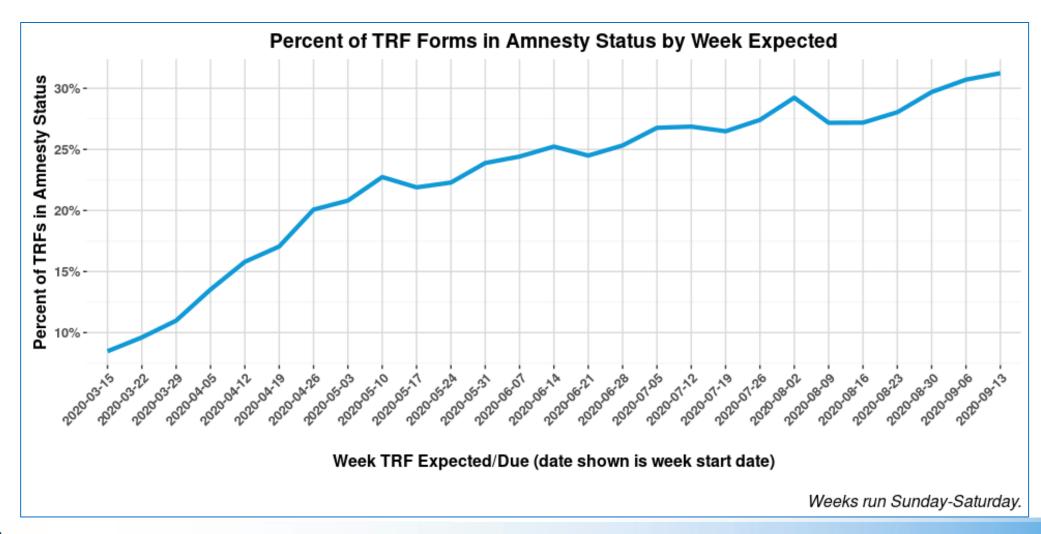
Follow-up Forms Amnesty: Data and Methods

- All TRF (transplant recipient follow-up) and LDF (living donor follow-up) forms due/expected between January 5, 2020 and September 19, 2020 compiled.
- Reporting of graft failures and patient deaths on TRF forms compiled based on the date form validated rather than the due date/expected date since the form can be from the original standard follow-up form.
- Based on OPTN data as of September 21, 2020.

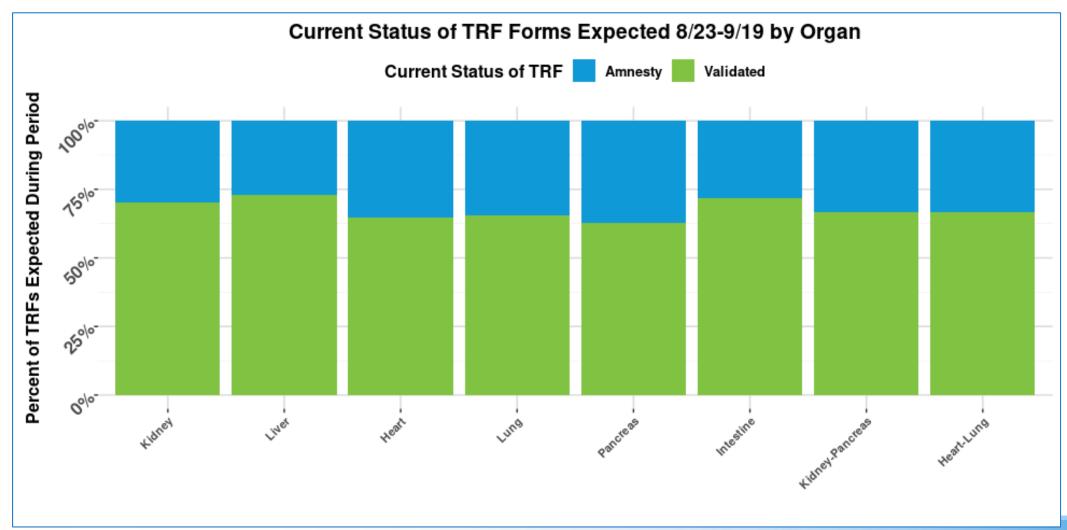
Recipient Follow-up: Status of Forms on 9/21 by Week Expected/Due



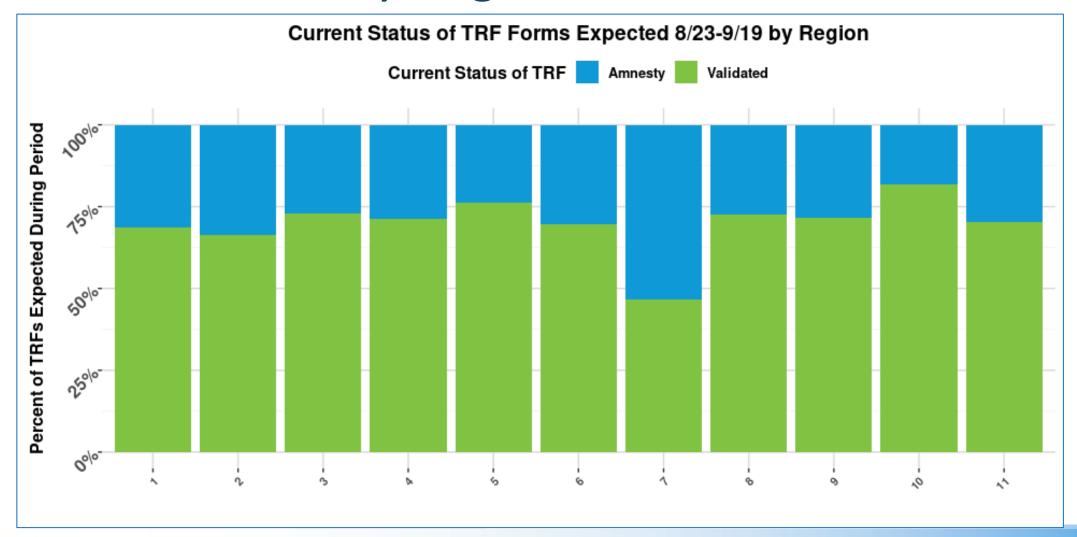
Recipient Follow-up: Percent in Amnesty Status on 9/21 by Week Expected/Due (3/15-9/19)



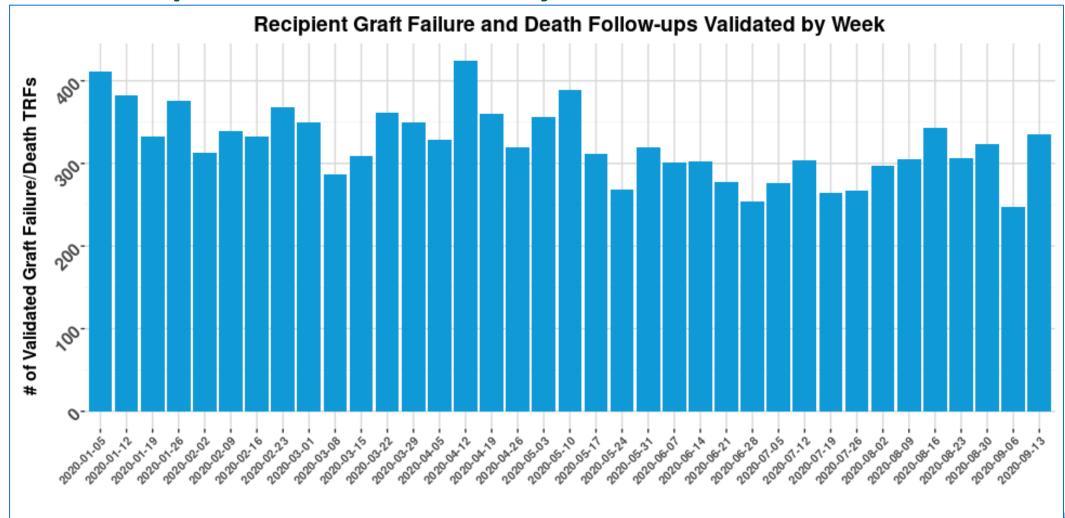
Recipient Follow-up: Status of Forms Expected 8/23-9/19 as of 9/21, By Organ



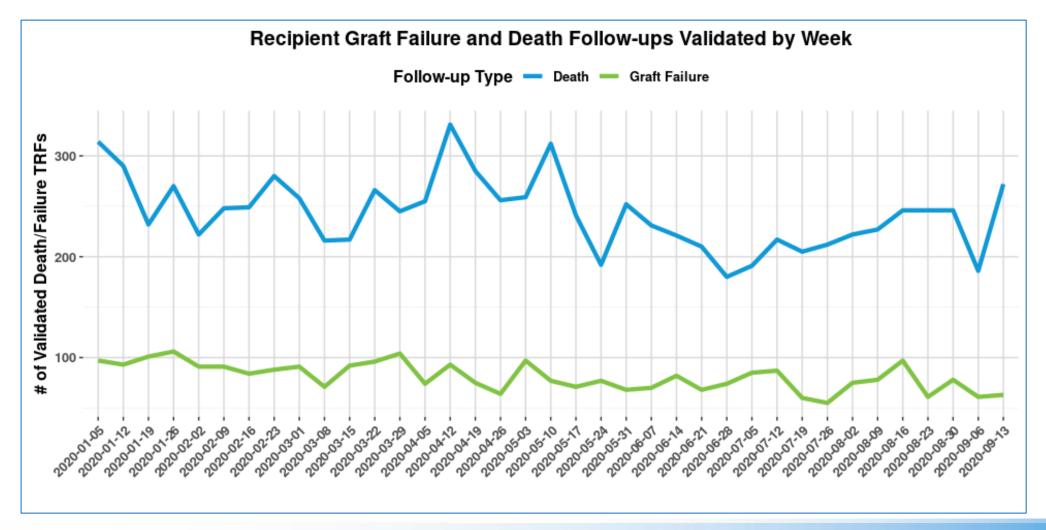
Recipient Follow-up: Status of Forms Expected 8/23-9/19 as of 9/21, By Region



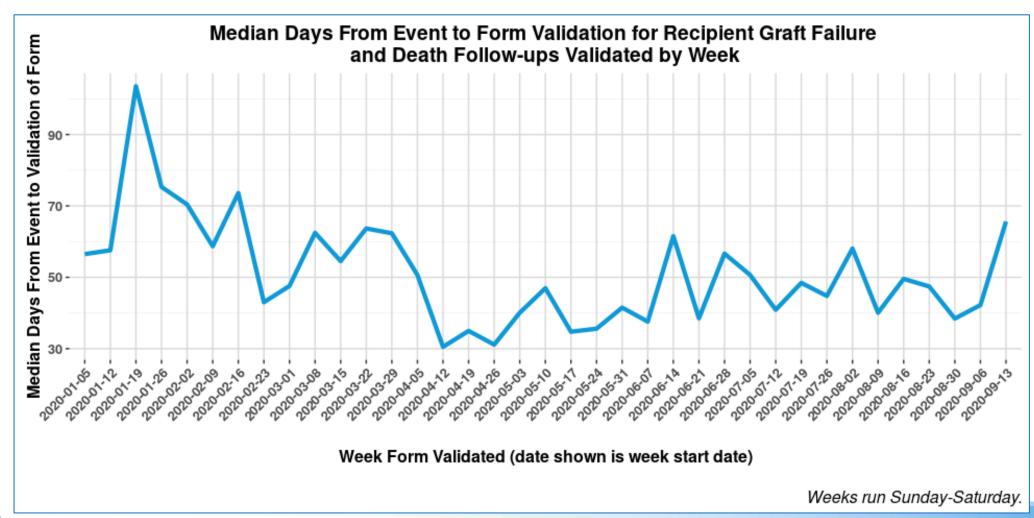
Recipient Follow-up: Graft Failure and Death Follow-ups Validated by Week



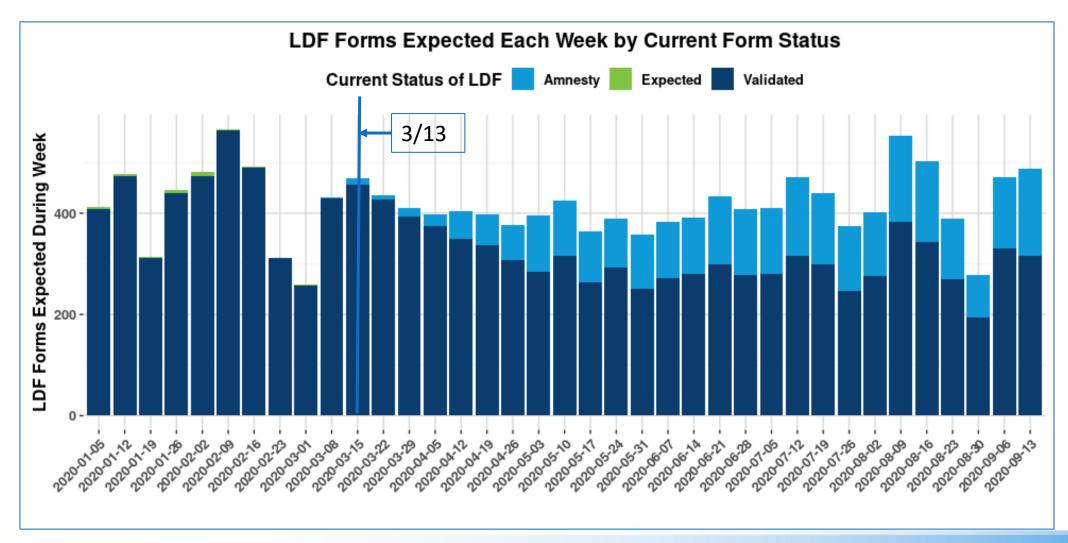
Recipient Follow-up: Graft Failure and Death Follow-ups by Type and Week Form Validated (1/5-9/19)



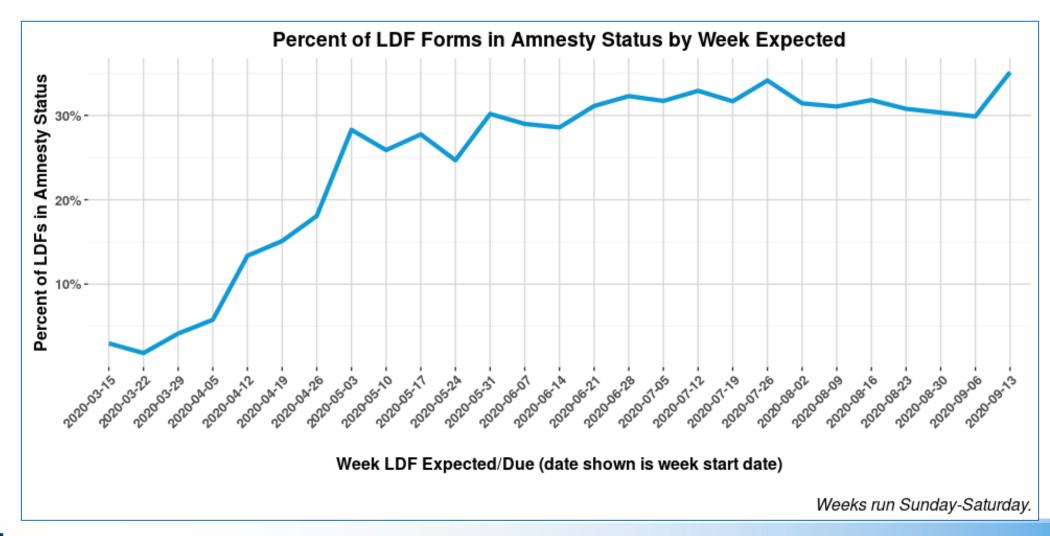
Recipient Follow-up: Median Days From Event to Validation for Failure/Death Follow-ups (1/5-9/19)



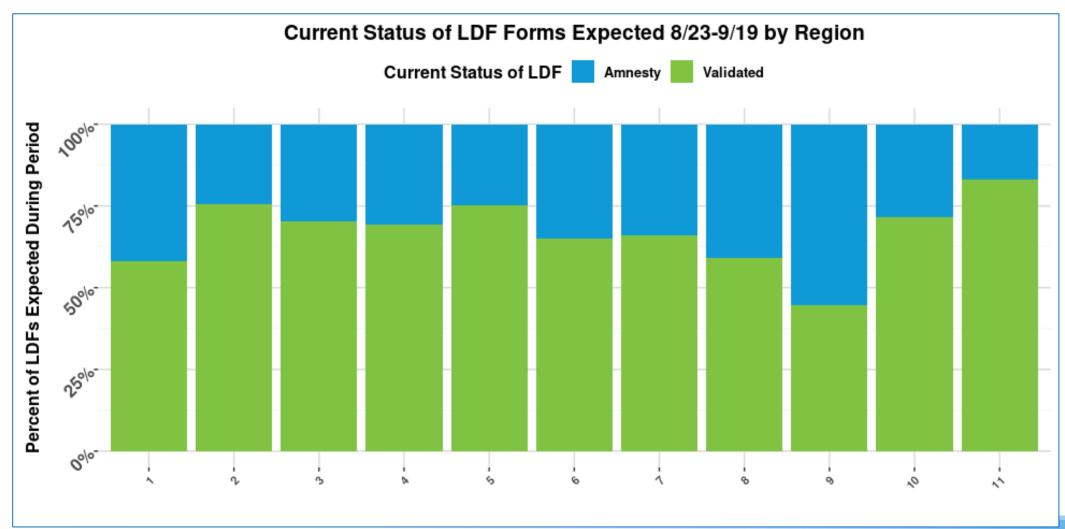
Living Donor Follow-up: Status of Forms on 9/21 by Week Expected/Due



Living Donor Follow-up: Percent in Amnesty Status on 9/21 by Week Expected/Due



Living Donor Follow-up: Status of Forms on 9/21 by Region for Forms Expected 8/23-9/19



Summary of COVID-19 Related TIEDI Changes

Policy changes currently in effect until December 31, 2020

LDF and TRF forms under amnesty status, but centers encouraged to provide available information

Reporting of graft failures and deaths still required, but allowed 30 days (instead of 14 days) between knowledge of event and reporting.

Changes to TIEDI Data Submission Requirements and "Data Lock"

December, 2019 OPTN Board of Directors passed Data Submission policy proposal from Data Advisory Committee

- Removal of policy 18.4 (Timely Data Submission)
- Additional 30 or 60 days for eight TIEIDI forms (LDR, LDF, TCR, TRR, TRF, DHS, RHS, DDR)
- Implementation of a data lock for those same eight forms.

Implementation currently delayed due to COVID-19

Tools developed to assist members (centers, OPOs, and labs) with these changes released on September 9th along with an educational offering in UNOS Connect

• Initially excluding TRF and LDF forms due to amnesty policy. Add to existing reports prior to implementation of data lock.

What is a "Data Lock"?

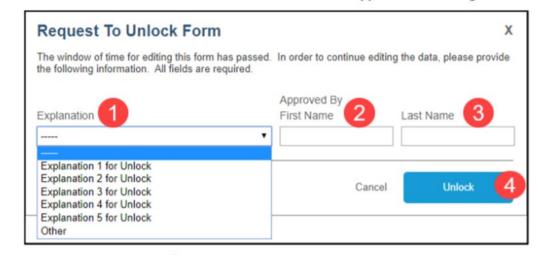
Forms will lock once they reach their due date (expected date). This includes both expected and validated forms.

Once a form is locked, data may only be added or modified by going through the manual unlocking process.

Unlocking a form requires providing a reason and the name of the person at their institution authorizing the change.

The form will automatically lock once changes are saved, requiring unlocking the form again to make additional changes.

Figure 2: Potential Way Members Will Have to Report a Reason for Changing Data and the Name of the Individual at the Member Institution Who Approved the Change



Purpose of New Data Quality Tools

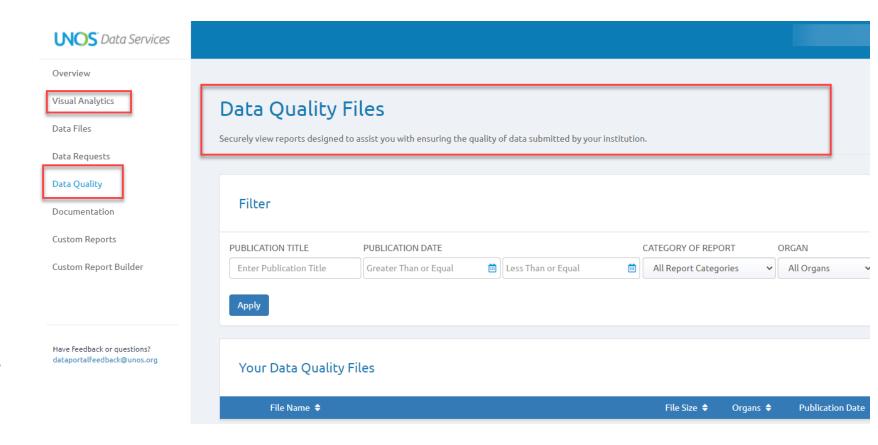
DATA LOCK PREVIEW REPORT (spreadsheets) provides OPTN members with an easy way to review and correct data submitted on impacted forms prior to the forms being "locked".

DATA LOCK DASHBOARD provides OPTN members with a dashboard to

- Compare the quality of their data to national results, resulting in identification of data elements consistently reported as unknown, etc.,
- Monitor changes in their overall and element specific data quality over time, and
- Review the frequency and reasons for "unlocking" forms at their institution.

Finding the Tools

- Data Lock Preview Report
 - Currently in "Data Files" section of Data Services portal
 - Soon available in new Data Quality section!!!
- Data Lock
 Dashboard available
 in Visual Analytics



Data Lock Preview Report and Data Lock Dashboard Demonstration

Questions?