

OPTN Data Advisory Committee (DAC) Report to the Board

Sumit Mohan, Chair

November 29, 2023

Objectives

- Share highlights of DAC's work over this past year and the key take aways from the OPTN data quality report
- Emphasize the importance of the of the OPTN data registry and the Board's prioritization in
 - Data quality initiatives
 - Reducing barriers to electronic data submission
 - Maturing data governance and data sharing
- Share the DAC's short and long-term recommendations

Data Review Report Highlights

- Changes to OPTN Data Collection (23 projects)
 - Reviewed changes to data collection (12 projects)
 - Focused on improving data quality (2 items)
 - Refusal code project monitoring
 - DAC Holistic Workgroup data definition clarification review
 - Summary of OPTN Data Changes
 - 2023 OMB approved changes implemented (509)
 - 2024 planned changes pending OMB approval (127)
- Improved Data Collection Definition/Instructions (14)
- Holistic Data Review Workgroup Activities
 - Participated in the Clinical Data Standards project
 - Worked on Data Definition Clarification requests

Data Quality Report Highlights

I. Dialysis Status

- Discrepancies in reported dialysis dates and statuses in OPTN Waiting List and TRR for KI

II. Timely data submission

- Institutional rates of timely form completion rose after Policy 18 change in August 2022

III. Review of 'data lock' activity since implementation

- Data lock activity varies by form (unlocking rates in TRF, TRR, and TCR forms are higher)
- Form unlocking activity peaks in April and October, corresponding data review periods before Program Specific Reports (PSR) release

IV. Analysis of cadence of data changes for forms pre-/post-lock implementation

- Fields critical to PSR risk adjustment are still being changed frequently post-lock

OPTN Data Registry

- Impacts operational workflows
- Used by medical research and practice
 - Growing demand to optimize patient care by implementing evidence-based medical interventions
 - Up-to-date data collection to support transplant practice and tools (advanced analytics)
- Should conform to clinical data and interoperability standards
 - Clinical data standards are essential to achieving reliable and accurate information exchange
 - Standardization makes it easy to combine data from different sources and enrich the data registry

Data Quality is Important

Operational workflows

OPTN community uses the data to benchmark performance and improve clinical practice

- Potential impact to OPTN-wide members
- Potential impact on government stakeholders



Desire for New Capabilities

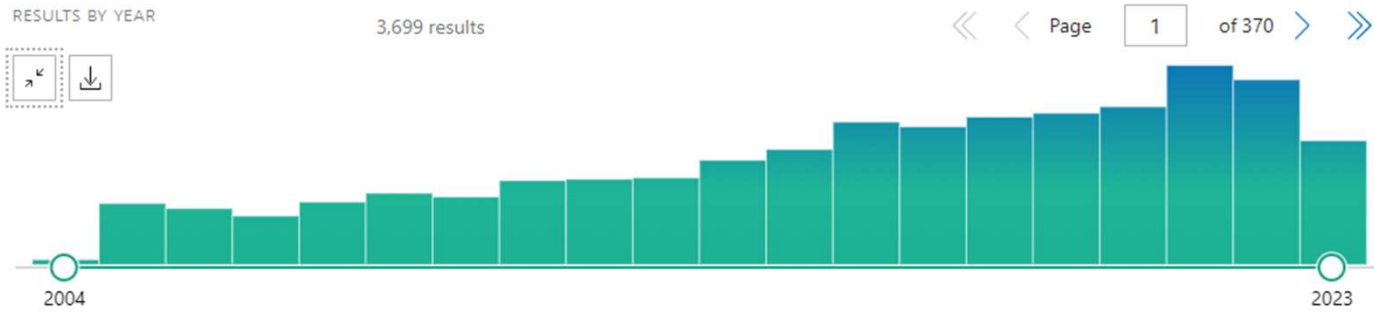
Operational workflows

How do we address the new wants or needs in the healthcare community?

- Data entry, abstraction and reporting
 - Search the donor and recipient records efficiently
- Information needs in transplant care
 - Improve care coordination between Organ Procurement Transplantation Network (OPTN) and non-OPTN providers (reduce the number of lost to follow up events)
 - Decision support – improved patient-level predictive modeling, assess graft failure risk, mortality risk and risk for other comorbidities
 - Health promotion – ability to track and monitor patients at risk/pre-organ failure

Community Interest in OPTN Data

Medical research and practice



Growing demand in scientific literature

Filters applied: 10 years. [Clear all](#)

> Am J Transplant. 2023 Sep 11;16(9):1600-1613. doi: 10.1016/j.ajt.2023.09.002. Online ahead of print.

Augmenting the U.S. Transplant Registry with External Mortality Data: A Moving Target Ripe for Further Improvement

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Abstract

The Organ Procurement and Transplantation Network conducts a robust death verification process when augmenting the United States transplant registry with external sources of data. Process enhancements added over 35,000 externally verified deaths across waitlist candidates and transplant recipients for all organs beginning in April 2022. Ninety-four percent of added post-transplant deaths occurred beyond five years post-transplant, and over 74% occurred beyond 10-years. Deceased donor solid organ recipients transplanted from 1/1/2010-10/31/2020 were analyzed from January and July 2022 OPTN Standard Transplant Analysis and Research and SRTR Standard Analysis Files to quantify the impact of including versus excluding unverified deaths (not releasable to researchers) on post-transplant patient survival estimates. Across all organs, one- and five-year post-transplant survival rates were not substantially impacted; meaningful differences were observed in 10-year survival among kidney recipients. These findings bear important implications for anyone who utilized transplant registry data to examine long-term outcomes prior to the updated verification process. Users of transplant surveillance data should interpret results of long-term outcomes cautiously, particularly differences across subpopulations, and the transplant community should identify ways to improve data quality while minimizing the data reporting burden from transplant institutions.

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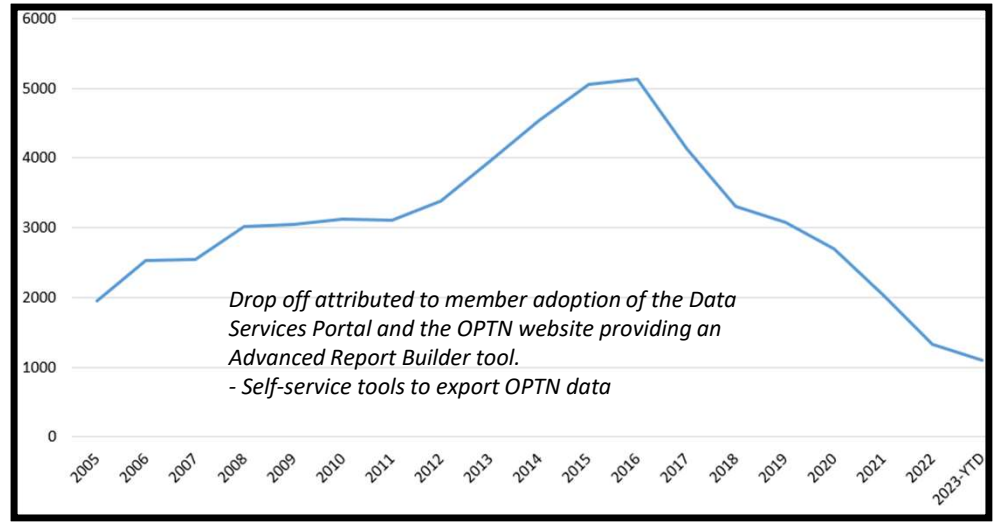
Used in national and international organ donation and transplantation statistics

Member Interest in OPTN Data

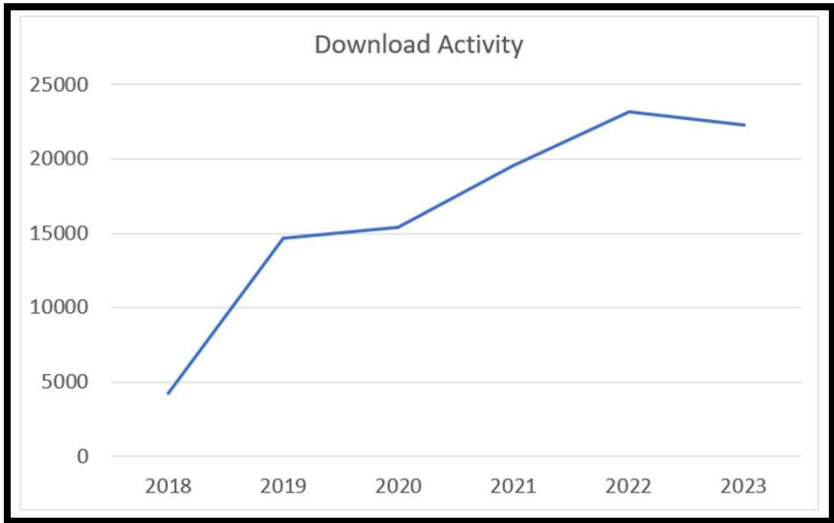
Medical research and practice

The demand for data has increased 5-fold since the implementation of self-service tools

Completed data requests since 2005



Data Portal activity since 2018

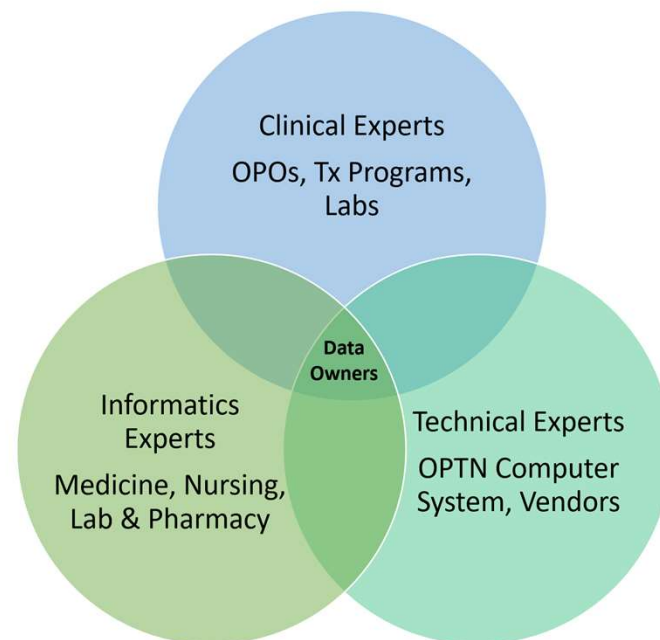


Prioritizing Data Quality Initiatives

Standards and interoperability

- Standardize the collection of shared data elements (between organs)
- Adopt health IT standards (terminology) and prioritize on technology roadmap
- Continuously assess community readiness and priorities
- Invest in skilled resources to improve data collection
- Establish a unified view of a patient record e.g., consolidate data from different external sources

Improving the registry requires engagement of broad expertise



Reducing Barriers to Electronic Data Submission

Standards and interoperability

- **Interoperability between member and OPTN system**
 - Custom OPTN API use vs manual data entry preferences
 - Site-level challenges? Informatics/technical resources, reporting timelines
 - Vendor challenges? Subjective mappings, vendor benchmarking

Electronic Data Submission Rates From August 2023

Match Data	Pre/Post Transplant Data	Month <input type="text" value="August 2023"/>
Deceased Donor Record Management 99.8%	Deceased Donor Reporting Forms 72.3%	Death Notifications Reporting Forms 89.6%
Transplant Candidate Record Management 71.1%	Candidate & Recipient Reporting Forms 47.7%	Living Donor Reporting Forms 26.6%

Mature Data Governance and Sharing

Standards and interoperability

- **Data is the cornerstone of the OPTN**
 - Used to inform allocation policy, measure equity, and regulatory measures and needs more investment
- **Data is mission critical to the OPTN's operations**
 - Better allocation requires a better assessment of the clinical characteristics of recipients and donors
 - A robust data strategy is essential for the registry to continue to inform clinical practice
 - Pushing the envelope requires close monitoring and evaluation
- **Data accuracy is essential**
 - Quality data is needed to assess the health of the transplant system
- **Data sharing between HHS agencies is critical**
 - Urgent action to resolve sharing impediments and data discrepancies

Recommendations for Improving OPTN Data Quality

Short-Term (1-2 years)

- Review transplant programs that are unlocking/editing data at higher rates to determine what action is needed (e.g., education, additional monitoring, enhancements, etc.)
- Perform additional analysis to understand the correlation between member data submission approach (electronic or manual) and unlocking activities
- Monitor and work with programs that have high rates of inconsistencies in dialysis dates to identify ways to reduce error rates
- Enhance Policy 18 to identify committee ownership and oversight for OPTN data and expectations for monitoring, measuring and managing data quality
- Review and update the OPTN Data Collection Principles and reimagine what the DAC should be in the future
- Identify data sharing improvement and efficiency opportunities between federal agencies and the OPTN

Recommendations for Improving OPTN Data Quality

Long-Term (2-3 years)

- Support HRSA and OPTN Board committing resources for the OPTN contractor to implement and sustain clinical data standards within the OPTN computer system

Questions & Discussion