OS-PCORTF Portfolio Year in Review

2024

The Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) brings together agency leaders, informaticians, technologists, and researchers across the U.S. Department of Health and Human Services (HHS) around the objective of **increasing data capacity for patient-centered outcomes research (PCOR).**

42 Projects in FY 2024

8 Completed Projects   **27** Continued Projects   **7** New Projects

OS-PCORTF projects collectively advance the ability of researchers to conduct patient-centered outcomes research by:
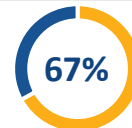
% Of Projects

Improving Data Access and Use
Through efforts that support timelier conduct of PCOR studies
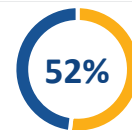
93%

Providing More Relevant Comprehensive Data
Through collection and integration of patient generated health data, inclusion of new variables, and data linkages
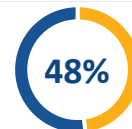
67%

Improving Data Quality
By addressing the completeness, accuracy, consistency, timeliness, and granularity of data that affect research conclusions for PCOR and CER

52%

Enhancing Analytic Resources
By improving or creating analytic resources for PCOR studies

48%

By leveraging **interagency collaborations**, OS-PCORTF funded projects improve the **rigor and usability of data resources** available for patient-centered outcomes research that aim to enhance evidence generation and decision making.

Enhancing HHS Interagency Relationships

95% of all projects involve interagency partnerships or collaborations.

Building on OS-PCORTF Foundational Work

50% of projects leverage work of prior OS-PCORTF projects, continuing to build towards the OS-PCORTF.

Addressing National Health Needs

ID/DD
2 projects

SDOH
23 projects

Cancer
3 projects

Artificial Intelligence & Digital Health
4 projects

Maternal Health
9 projects

Emergent Health Threats
11 projects

Substance Use Disorder
4 projects

Maternal Health

Nine projects improved the data available for maternal and child health research that aim to reduce maternal morbidity and mortality rates and investigate disparities in health outcomes. Through data linkages, addition of new variables, and standardization of data elements, in key data sources such as electronic health records, projects will facilitate access to comprehensive, longitudinal maternal health data to study maternal outcomes and inform evidence-based health policy and treatment guidelines.

Intellectual and Developmental Disabilities (ID/DD)

Two projects address gaps in PCOR data infrastructure for ID/DD by developing standardized methods for identifying functional disability status and promoting inclusion of disability status in federal datasets through new linkages. Researchers can use these linked data to assess relationships between sociodemographic factors, service utilization, and person-centered outcomes for people with ID/DD.

Substance Use Disorder (SUD)

Four projects build data capacity to study SUD treatments' impact on patient-centered outcomes. Through linked datasets, expanded data collection and inclusion of SUD-relevant variables in databases, and development of new approaches to identify substance-involved encounters in hospital data, these projects provide researchers with additional information to understand the relationship between care utilization, federal- and state-funded program participation, and health outcomes.

Cancer

Three projects are developing data resources for cancer PCOR, including data exchange standards, linked datasets, and linkage governance frameworks, which will promote the secure linkage of cancer-related data across agencies and improve researchers' access to clinical data on cancer care to study cancer health outcomes.

Emergent Health Threats

Eleven projects are linking data, developing standards for linking and sharing data across disparate sources, and expanding collection of relevant data variables to facilitate research on the impact of emergent health threats on patient-centered outcomes. Researchers can leverage these data products to explore the relationships between community factors, the environment, and service utilization during health emergencies, such as climate change and the COVID-19 pandemic, on patient outcomes.

Social Determinants of Health (SDOH)

Twenty-three projects are addressing health disparities by leveraging SDOH data to strengthen evidence of the impact of SDOH factors on patient-centered outcomes for understudied and underserved populations. Projects link longitudinal SDOH, clinical, and administrative data to improve researchers' ability to study how geographic location, environmental factors, socioeconomic status, health care coverage, and other influences affect health care utilization and outcomes in underserved populations.

Artificial Intelligence (AI) and Digital Health

Four projects will advance the use of AI and digital health tools for PCOR by developing new privacy-preserving machine learning and natural language processing techniques that improve data standardization, linkage, and exchange. These approaches will make clinical EHR data, unstructured hospital data, and data from health information exchanges more readily available to researchers to answer PCOR questions for several use cases including COVID-19, substance use disorder, and cancer.

PCOR Data Infrastructure Resources

48 products were produced by the **8** OS-PCORTF projects completed in FY 2024.

These products improve researchers' ability to efficiently conduct effective, high-quality patient-centered outcomes research.

Project Reports & Publications	User Implementation Tools & Guides	Databases & Datasets	Health IT Standard	Open-Source Code	Data Element & Informational Model	End User Feedback & Training	Data Collection Methods
21	9	7	5	3	1	1	1

Completed FY 2024 Projects

CURE ID: Aggregating and Analyzing COVID-19 Treatment from EHRs and Registries (FDA)

The **CURE ID Database** captures over 130,000 COVID-19 treatment cases, including patient-submitted cases on long COVID, for studying COVID-19 treatment efficacy.[1]

Data Linkage: Evaluating Privacy Preserving Record Linkage Methodology and Augmenting the National Hospital Care Survey with Medicaid Administrative Records (CDC)

The project's enhanced **linkage algorithm** improves the accuracy and efficiency of linking National Hospital Care Survey (NHCS) and CMS data. Augmented **linked 2014 and 2016** NHCS-CMS datasets are available in the CDC Research Data Center.[2,3]

Developing a Multi-State Network of Linked Pregnancy Risk Assessment Monitoring System (PRAMS) and Clinical Outcomes Data for Patient-Centered Outcomes Research (CDC)

State agencies can use the PRAMS linkage **framework** to implement sustainable linkage systems that integrate PRAMS data with administrative data sources to better understand drivers of maternal health outcomes.[4]

Human-Centered Design Study on Federal Data Access and Acquisition Processes of CMS Data (CMS)

CMS' human-centered design study **project report** highlights opportunities for streamlining data access processes for federal agencies.[5]

Linking State Medicaid and Child Welfare Data for Outcomes Research on Treatment for Opioid Use Disorder (OUD) and Other Behavioral Health Issues (ASPE/ACF)

A de-identified **dataset** containing linked child welfare records and caregivers' Medicaid data in Florida and Kentucky is available to researchers to study parental OUD and child welfare involvement and outcomes.[6]

Making Electronic Health Record (EHR) Data More Available for Research and Public Health (CDC)

The MedMorph data exchange system facilitates sharing EHR data with public health agencies. System developers can use the **five Health Level 7 (HL7) Fast Healthcare Interoperability Resources (FHIR®) Implementation Guides** to implement the MedMorph reference architecture for four use cases.[7] Open-source code for the **FHIR app** used in MedMorph is available.[8]

MAT-LINK2: Expansion of MATernaL and Infant NetworK (MAT-LINK) to Understand Outcomes Associated with Treatment for Opioid Use Disorder during Pregnancy (CDC)

The expanded **MAT-LINK dataset** captures a more geographically, racially diverse set of pregnant woman-infant dyads and additional variables to study child outcomes associated with medication for OUD during pregnancy.[9]

Severe Maternal Morbidity and Mortality EHR Data Infrastructure (NIH)

The MaternalHealthLink **web application** and accompanying **HL7 FHIR standard and Implementation Guide** enable extraction and exchange of maternal and infant EHR and vital records data for research on maternal mortality.[10,11]

References

[1] Cure ID [dataset]. U.S. Food and Drug Administration, and National Center for Advancing Translational Science, National Institutes of Health. **https://cure.ncats.io/**

[2] Restricted-Use Linked NHCS-CMS Medicaid Data. National Center for Health Statistics, Centers for Disease Control and Prevention. **https://www.cdc.gov/nchs/data-linkage/nhcs-medicaid.htm**

[3] Restricted-Use Linked NHCS-CMS Medicare Data. National Center for Health Statistics, Centers for Disease Control and Prevention. **https://www.cdc.gov/nchs/data-linkage/CMS-Medicare-Restricted.htm**

[4] Parrish J, Strahle S, Vance S. A Framework for Linking PRAMS with Administrative Data; 2024. **https://www.astho.org/topic/report/framework-linking-prams-with-administrative-data/**

[5] Office of Enterprise Data and Analytics, Centers for Medicare and Medicaid Services. *Human-Centered Design Study on Federal Data Access and Acquisition Processes of CMS Data Final Report 2023;* 2023**. https://aspe.hhs.gov/sites/default/files/documents/c0ec82bd6725b12c7d0a119f0ff9811d/cms-human-centered-design-study.pdf**

[6] Mark TL, Dolan M, Allaire B, Smith K, Parish W, Bradley C, Madden E, Butler V. Child and Caregiver Outcomes Using Linked Data [dataset]. National Data Archive on Child Abuse and Neglect; 2022. doi: **https://doi.org/10.34681/33ge-9z29**

[7] Making Electronic Data More Available for Research and Public Health (MedMorph). Health Level Seven; June 8, 2023. **http://hl7.org/fhir/us/medmorph/ImplementationGuide/hl7.fhir.us.medmorph**

[8] eCRNow, Version 3.1.5. GitHub; September 16, 2024. **https://github.com/drajer-health/eCRNow**

[9] MATernal and Infant Clinical Network (MAT-LINK) [dataset]. Centers for Disease Control and Prevention; 2024. **https://www.cdc.gov/rdc/b1datatype/mat-link.htm**

[10] Nih-mmm-032023. GitHub; October 12, 2023. **https://github.com/lantanagroup/link/releases/tag/nih-mmm-032023**

[11] Longitudinal Maternal & Infant Health Information for Research. Health Level Seven; March 29, 2023. **https://hl7.org/fhir/us/mihr/STU1/**