2025

OS-PCORTF Portfolio Year in Review

The Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) **works to build data capacity for patient-centered outcomes research (PCOR) and comparative clinical effectiveness research (CER).** It does so through a portfolio of projects developed, implemented, and coordinated in partnership with United States (U.S.) Department of Health and Human Services (HHS) agencies. By engaging HHS agency leaders, informaticians, technologists, researchers, decision makers, and patients, OS-PCORTF projects develop relevant and sustainable data resources that make it easier for researchers and private sector stakeholders to collect, link, and analyze data that can lead to more patient-centered care.

37 Projects in Fiscal Year 2025

15 Completed Projects

19 Continued Projects

3 New Projects

OS-PCORTF projects collectively strengthen the infrastructure for patient-centered outcomes research and CER by:

	% Of Projects
Improving Data Access and Use Through efforts that support timelier conduct of PCOR studies	97%
Providing More Relevant Comprehensive Data Through collection and integration of patient generated health data, inclusion of new variables, and data linkages	68%
Improving Data Quality By addressing the completeness, accuracy, consistency, timeliness, and granularity of data that affect research conclusions for PCOR and CER	65%
Enhancing Analytic Resources By improving or creating analytic resources for PCOR studies	43%

The OS-PCORTF portfolio enhances HHS interagency **infrastructure for collaboration** and strengthens **the efficiency of data infrastructure activities** across federal initiatives.

95%

Enhancing HHS Interagency Relationships

of all projects involve interagency partnerships or collaborations.

62%

Building on OS-PCORTF Foundational Work

of projects leverage work of prior OS-PCORTF projects, ensuring continuity throughout the portfolio.

Addressing HHS National Priorities and Clinical Areas

Preventing & Managing Chronic Diseases
11 Projects

Maternal & Pediatric Health
10 Projects

Artificial Intelligence & Synthetic Data Creation
3 Projects

Enhancing Data Transparency & Reproducibility
5 Projects

Gathering Patient-Reported Data
4 Projects

Intellectual & Developmental Disabilities
2 Projects

Facilitating Research for Medicaid Beneficiaries
8 Projects

Preventing and Managing Chronic Diseases

Eleven projects improve data quality, robustness, and interoperability to support chronic disease prevention and management. Efforts include expanding common data models, developing data standards, linking data sources, and developing governance frameworks for secure data sharing. Projects also advance the patient-centeredness of chronic disease research by creating tools to capture patient and caregiver-reported outcomes.

Maternal and Pediatric Health

Ten projects support the OS-PCORTF priority to strengthen data infrastructure for maternal and pediatric health research. These initiatives promote data standardization and harmonization, enable linkages across data sources, and develop publicly accessible datasets. Together, these efforts support robust research on how exposures and treatments during and after pregnancy affect meaningful maternal and child health outcomes.

Artificial Intelligence (AI) & Synthetic Data Creation

Three projects expand access to clinical data for research while protecting privacy. One project uses AI for predictive modeling, one project uses AI to identify substance use outcomes, and one project created synthetic linked datasets that maintain real-world accuracy while safeguarding patient privacy.

Enhancing Data Transparency & Reproducibility

Five projects promote data transparency through resources that enhance researchers' understanding of the strengths, limitations, creation and reproducibility methodologies, and appropriate applications of linked data. Resources include metadata standards, technical assistance tools, and governance frameworks.

Gathering Patient-Reported Data

Four projects facilitate the capture of outcomes that reflect the priorities and experiences of patients and caregivers by developing patient-reported data collection tools and surveys. By standardizing such data, projects enable the use of high-quality patient-reported data in research to support generation of more patient-centered evidence.

Intellectual and Developmental Disabilities (ID/DD)

Two projects aim to improve the quality and availability of data on individuals with ID/DD in administrative and clinical data, enhancing insights into point-of-care experiences, health care utilization and spending, delivery system performance, and outcomes for this population.

Facilitating Research for Medicaid Beneficiaries

Eight projects enhance the quality of T-MSIS and Medicaid data by standardizing the data to different formats for more efficient PCOR and CER analyses. They also strengthen Medicaid data infrastructure by linking T-MSIS data with clinical, survey, and administrative sources to study health outcomes across the full trajectory of Medicaid beneficiaries' care and assess treatment effects of federal programs and interventions.

PCOR Data Infrastructure Resources

53 products were produced by the OS-PCORTF projects completed in Fiscal Year 2025. These products improve researchers' ability to efficiently conduct effective, high-quality patient-centered outcomes research.

Project Reports & Publications	User Implementation Tools & Guides	Databases & Datasets	Software & Analytic Services	Data Governance	Health IT Standards	Data Element & Informational Model
19	16	8	5	3	1	1

Building Infrastructure and Evidence for COVID-19 Related Research, Using Integrated Data (CDC/NCHS)

Created a synthetic linked dataset combining data from the NHIS, CMS, and HUD to study the effect of non-medical factors on chronic diseases.[1] Also produced a data dictionary with 51 data elements and a user guide for researchers.[2,3] A second NHCS-NDI synthetic linked dataset, data dictionary, and user guide will be released in 2026.

Compendium of Policies on Use of Linkable Mortality Data for PCOR in the Nation's 57 Mortality-Reporting Jurisdictions (ASPE/BHDAP)

Summarized the methodology for developing a database on mortality policies from 57 U.S. jurisdictions, including best practices to improve research on survival outcomes in the Mortality for Data Linkages for Research Report.[4] The searchable database on mortality policies will be available in 2026.

Creating a Federal COVID-19 Longitudinal Patient Outcomes Research Database Linked to Health Systems and Clinical Data (NIH)

Created a linked dataset and accompanying methodology report from CMS claims data and electronic health record data from the NCATS N3C.[5] Offers a public N3C Privacy Preserving Record Linkage (PPRL) Enrichment Dashboard describing how N3C data are enriched through PPRLs with CMS claims data.[6]

Data Capacity for Patient-Centered Outcomes Research through Creation of an Electronic Care Plan (eCare Plan) for People with Multiple Chronic Conditions 2.0: Development of the Patient-Facing Application (AHRQ/NIH/NIDDK)

Provides the source code and an implementation guide for MyCarePlanner, allowing health systems to deploy a patient-facing eCare Plan app that integrates with the clinician-facing eCarePlanner to share patient-reported data.[7,8,9]

Enhancing Surveillance of Maternal Health Clinical Practices and Outcomes with Federally Qualified Health Centers' Electronic Health Records Visit Data (CDC)

Developed a nationally representative Federally Qualified Health Center dataset and accompanying user documentation from NAMCS. Also produced NAMCS-NDI and NAMCS-HUD linked data files, allowing researchers to study mortality outcomes and upstream influences.[10,11,12]

Evaluation of Privacy-Preserving Record Linkage Solutions to Broaden Linkage Capabilities in Support of Patient-Centered Outcomes Research Objectives (CDC/NCHS)

Assessed deployment of an open-source PPRL software within the NCHS computing environments. Evaluation findings, including strengths and limitations of the PPRL software, will be shared in a forthcoming manuscript.

Making Medicaid Data More Accessible Through Common Data Models and FHIR APIs (FDA/NIH/NLM)

Created open-source codes[13,14] and user guides[15,16] for mapping T-MSIS data to OMOP and Sentinel common data models. Also provides a T-MSIS dataset in the Sentinel common data model format and accompanying open-source linkage code for maternal and infant outcomes research.[17]

Understanding Long-term Outcomes in COVID-19 Survivors with Multiple Chronic Conditions (MCC) through eCare Plan Development (AHRQ/NIH/NIDDK)

Expanded the source code and implementation guide for eCarePlanner to address over 1,100 data elements and value sets relevant to chronic kidney disease, diabetes, cardiovascular disease, chronic pain, and Long COVID, enabling standardized data collection.[8,9,18] Additionally, added a caregiver-facing interface to MyCarePlanner.[7]

Abbreviations: AHRQ: Agency for Healthcare Research & Quality; ASPE: Assistant Secretary for Planning and Evaluation; BHDAP: Office of Behavioral Health, Disability, and Aging Policy; CDC: Centers for Disease Control and Prevention; CMS: Centers for Medicare & Medicaid Services; FDA: Food and Drug Administration; HUD: U.S. Department of Housing and Urban Development; NAMCS: National Ambulatory Medical Care Survey; NCHS: National Center for Health Statistics; NCATS: National Center for Advancing Translational Sciences; NDI: National Death Index; NHCS: National Hospital Care Survey; NHIS: National Health Interview Survey; NIDDK: National Institute of Diabetes and Digestive and Kidney Diseases; NIH: National Institutes of Health; NLM: National Library of Medicine; N3C: National COVID Cohort Collaborative; OMOP: Observational Medical Outcomes Partnership; T-MSIS: Transformed Medicaid Statistical Information System.

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