



The 2023 Annual Portfolio Report

Building Data Capacity for the Office of the Secretary
Patient-Centered Outcomes Research Trust Fund (OS-PCORTF)

Patient-centered outcomes research (PCOR) aims to produce robust evidence about the outcomes and effectiveness of treatments, services, and other health care interventions important to patients, caregivers, clinicians, and policymakers. The success of patient-centered outcomes research is dependent on infrastructure that promotes the availability and accessibility of high-quality data and related data resources. In turn, these data can enhance patient, caregiver, clinician, and policymaker decision-making through evidence generation.

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) coordinates the U.S. Department of Health and Human Services' (HHS's) Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF).

MISSION

Build and strengthen data capacity for patient-centered outcomes research through coordination across agencies and federal programs.

VISION

Better data for patient-centered outcomes research to improve evidence generation, decision-making, and health outcomes for all Americans.

To achieve both the mission to build and strengthen data capacity for patient-centered outcomes research, and the vision of better data to generate stronger evidence and foster informed decisions, the [OS-PCORTF Strategic Plan 2020-2029](#) identified four goals grounded in the principles of person-centeredness, collaboration, innovation, and impact.¹

STRATEGIC PLAN



GOAL 1

Data Capacity for National Health Priorities



GOAL 2

Data Standards and Linkages for Longitudinal Research



GOAL 3

Technology Solutions to Advance Research



GOAL 4

Person-Centeredness, Inclusion, and Equity

This Annual Portfolio Report describes the accomplishments of the OS-PCORTF during Fiscal Year (FY) 2023. The OS-PCORTF portfolio includes multi-agency projects and consortia that collectively contribute to achieving the Strategic Plan goals and strengthen data capacity for patient-centered outcomes research and comparative clinical effectiveness research (CER) across key national and HHS health priorities. The report is organized by the following sections:

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- **Project Contributions**: Contributions of the 36 active FY 2023 OS-PCORTF projects to the four Strategic Plan goals.
- **Portfolio-Wide Accomplishments**: OS-PCORTF programmatic accomplishments and activities to advance PCOR data capacity.
- **Appendix A**: Additional information on the four projects that concluded in FY 2023, including impacts on expanding data capacity for patient-centered outcomes research, and available data and technical products developed by the projects.
- **Appendix B**: Overview of the 12 projects newly funded in FY 2023.





FY 2023 Project Contributions to the OS-PCORTF Strategic Plan



Each of the 36 active OS-PCORTF projects uniquely advances the portfolio’s progress toward achieving the Strategic Plan goals. While several active projects address multiple Strategic Plan goals, as indicated with an asterisk, each project is listed once under the goal with which it most closely aligns. The OS-PCORTF website provides information on the entire [OS-PCORTF portfolio](#), including past projects.

20 Projects in Progress

4 Completed Projects

12 New Projects

ACCOMPLISHMENTS IN DATA INFRASTRUCTURE

25 data and technical products were produced by the 4 OS-PCORTF projects completed in FY 2023.

These products enhance researchers’ **capacity to conduct robust patient-centered outcomes research** to address critical PCOR questions across areas like **substance use disorder, maternal health, and health equity**.



Project Reports & Publication

15



User Implementation Tools & Guides

5



Databases & Datasets

2



Data Element & Information

1



Health IT Standard

1



Open-Source Code

1

Goal 1. Data Capacity for National Health Priorities



The OS-PCORTF aims to improve PCOR data capacity for several key national and HHS health priorities, such as cancer care, maternal health, intellectual and developmental disabilities (ID/DD), as well as national emergencies such as the opioid overdose crisis and COVID-19. In FY 2023, 14 projects worked to address the needs of researchers, patients, clinicians, and policymakers in these areas. Specifically, these projects are creating more comprehensive datasets through data linkages, improving data quality through standardized data capture and development of new data standards, and improving the availability and accessibility of data for PCOR studies through research network collaboration.

8 Projects in Progress

3 Completed Projects

3 New Projects

To advance Goal 1, three new projects were funded in FY 2023.

One project will produce linkages between cancer registries and electronic health record (EHR) data to study cancer outcomes.

Two projects will improve the utility of Medicaid data by linking claims and clinical data to support improved research on maternal and infant health outcomes.



Explore Projects Further

Projects New in FY 2023

[Capturing the Full Trajectory of Patient-Centered Cancer Care Via Enhanced Data Linkages* \(NIH/NCI, NIH/NCATS\)](#)

[Improving Quality of Care & Outcomes Data for Pregnant Medicaid Beneficiaries & Newborn Infants* \(CMS\)](#)

[Linking Federally Qualified Health Center EHR and Medicaid Data for Increased Data Capacity to Understand Maternal Health Care* \(CDC/NCHS, ASPE\)](#)

Projects in Progress in FY 2023

[Building Infrastructure and Evidence for COVID-19 Related Research, Using Integrated Data* \(CDC/NCHS\)](#)

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

[Developing a Multi-State Network of Linked Pregnancy Risk Assessment Monitoring System \(PRAMS\) and Clinical Outcomes Data for Patient-Centered Outcomes Research* \(CDC/DRH\)](#)

[Enhancing Surveillance of Maternal Health Clinical Practices and Outcomes with Federally Qualified Health Centers' Electronic Health Records Visit Data* \(CDC/NCHS\)](#)

[Linking State Medicaid and Child Welfare Data for Outcomes Research on Treatment for Opioid Use Disorder and Other Behavioral Health Issues* \(ASPE, ACF/OPRE\)](#)

[MAT-LINK2: Expansion of MATernal and Infant Network to Understand Outcomes Associated with Treatment for Opioid Use Disorder during Pregnancy* \(CDC\)](#)

[Severe Maternal Morbidity and Mortality EHR Data Infrastructure* \(NIH\)](#)

[Understanding COVID-19 Trajectory and Outcomes in the Context of Multiple Chronic Conditions \(MCC\) through e-Care Plan Development* \(AHRQ, NIH/NIDDK\)](#)

Completed in FY 2023, [Addiction Medicine Practice Based Research Network \(AMNet\)](#) advances Goal 1 by enhancing access to real-time clinical and patient-reported OUD data for researchers, improving surveillance and clinical decision-making. Aggregated and standardized data include patient-reported outcome measures (PROMs), medication for opioid use disorder (MOUD) treatment recovery service utilization, and OUD patient outcomes, all of which contribute to providing access to more comprehensive, relevant data for patient-centered outcomes research.



Explore Project Further

Projects Completed in FY 2023

[AMNET: An Addiction Medicine Network to Address the United States Opioid Crisis \(NIH/NIDA\)](#)

[Enhancing Identification of Opioid-Involved Health Outcomes Using Linked Hospital Care and Mortality Data* \(CDC\)](#)

[Surveillance Network: Maternal, Infant, and Child Health Outcomes Following Treatment of Opioid Use Disorder \(OUD\) During Pregnancy* \(CDC\)](#)

*Denotes that the project addresses more than one Strategic Plan goal.



Goal 2. Data Standards and Linkages for Longitudinal Research



Eleven projects primarily focused on providing more relevant and comprehensive data to support longitudinal research. They achieved this by improving the interoperability and comprehensiveness of datasets that integrate variables from several data sources, including national-level surveys, federal and state program data, and EHR data. These projects extend the availability of longitudinal health outcomes data that span patients' lives, care settings, and clinical trajectories, which are needed to generate evidence to support informed decision-making and improve health outcomes.

7 Projects in Progress

4 New Projects

In FY 2023, four new projects were funded that directly address Goal 2.

Together, these new projects will improve the interoperability of data across research networks, provide guidance to researchers to access mortality data, produce data linkages between survey data and Medicaid claims to study pediatric COVID-19 cases, and harmonize disparate sources to create new state-based encounter-level databases.



Explore Projects Further

Completed in FY 2023, the [MATernal and Infant Network to Understand Outcomes Associated with Medication for Opioid Use Disorder during Pregnancy \(MAT-LINK2\)](#) surveillance network addressed Goal 1 and Goal 2 through adding over 3,000 more linked pregnant person-infant pairs with OUD to the MATLINK dataset and extending follow-up data collection for children from two to six years of age resulting in a higher-quality research dataset.



Explore Project Further

Projects New in FY 2023

[Code Map Services for Interoperability of Common Data Models and Data Standards*](#) (NIH/NCATS, FDA)

[Compendium of Policies on Use of Linkable Mortality Data for PCOR in the Nation's 57 Mortality-Reporting Jurisdictions \(ASPE/BHDAP, NIH/NIMH\)](#)

[Linking the National Survey of Children's Health Longitudinal Cohort and Medicaid Claims Data to Explore Pediatric COVID-19*](#) (HRSA/MCHB)

[Panoramic View of Patient Care Through Data Innovations and Linkages*](#) (AHRQ)

Projects in Progress in FY 2023

[Creating a Federal COVID-19 Longitudinal Patient Outcomes Research Database Linked to Health Systems and Clinical Data*](#) (NIH/NCATS)

[Data Linkage: Evaluating Privacy Preserving Record Linkage Methodology and Augmenting the National Hospital Care Survey with Medicaid Administrative Records \(CDC/NCHS\)](#)

[Digitizing Consent and Regulatory Metadata Towards Streamlining Governance of Pediatric COVID-19 Research Data Linkages*](#) (NIH/NICHD)

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

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

[Making Medicaid Data More Accessible Through Common Data Models and FHIR APIs*](#) (FDA, NIH/NLM)

[Multistate Emergency Medical Services \(EMS\) and Medicaid Dataset \(MEMD\): A Linked Dataset for PCOR*](#) (ASPE/BHDAP)

*Denotes that the project addresses more than one Strategic Plan goal.

Goal 3. Technology Solutions to Advance Research



OS-PCORTF projects use analytic tools such as artificial intelligence (AI), including machine learning, and privacy-preserving data linkage methods to improve the availability and interoperability of data used to answer PCOR questions. In FY 2023, three projects used such technology solutions to facilitate real-time data exchange between health systems, researchers, and public health authorities, and to increase the availability of clinical data from EHRs for research. These projects have developed resources including Fast Healthcare Interoperability Resources (FHIR®) application programming interfaces (APIs) that share data while protecting individuals’ privacy, as well as machine learning techniques such as natural language processing and split learning to facilitate access to previously inaccessible EHR data for PCOR studies.

2 Projects in Progress

1 New Project

The new FY 2023 project [Utilizing Natural Language Processing and Machine Learning to Enhance the Identification of Stimulant and Opioid-Involved Health Outcomes in the National Hospital Care Survey](#) advances Goal 3 by using AI techniques to improve the identification of stimulant- and opioid-involved hospital encounters based on both structured and unstructured data to enhance the 2020 National Hospital Care Survey (NHCS) restricted use dataset.

 [Explore Project Further](#)

Projects New in FY 2023

[Utilizing Natural Language Processing and Machine Learning to Enhance the Identification of Stimulant and Opioid-Involved Health Outcomes in the National Hospital Care Survey* \(CDC/NCHS\)](#)

Projects in Progress in FY 2023

[Making Electronic Health Record \(EHR\) Data More Available for Research and Public Health \(CDC\)](#)

[Using Machine Learning Techniques to Enable Health Information Exchange \(HIE\) Data Sharing to Support COVID-19-focused PCOR* \(ONC\)](#)

*Denotes that the project addresses more than one Strategic Plan goal.

The newly linked [2014 and 2016 National Hospital Care Survey, National Death Index, and Drug-Involved Mortality datasets](#) addressed Goal 1 by improving the availability of more comprehensive clinical data on hospital care and deaths related to opioid-involved drug overdose for OUD outcomes research. Moreover, the [Enhancing Identification of Opioid-Involved Health Outcomes Using Linked Hospital Care and Mortality Data](#) project aligns with Goal 3 by developing [natural language processing algorithms](#) to enhance the identification of opioid-involved health outcomes and co-occurring SUD and mental health issues in federal datasets.

 [Explore Project Further](#)

Goal 4. Person-Centeredness, Inclusion, and Equity



In FY 2023, OS-PCORTF projects enhanced the capacity to generate evidence to improve health outcomes for underserved and marginalized populations, including individuals experiencing social risk(s), people with ID/DD, refugees, people living with multiple chronic conditions (MCC), and those disproportionately affected by climate change. Eight projects improved the quality of data for patient-centered outcomes research by facilitating the collection and sharing of social determinants of health (SDOH), patient-reported outcomes, and demographic data to improve care coordination, track outcomes, and strengthen representation in datasets. OS-PCORTF projects also supported the development of patient- and clinician-facing applications that aggregate and share data important to patients across health care settings to improve care coordination and facilitate patient-centered outcomes research.

3 Projects in Progress

1 Completed Project

4 New Projects

The OS-PCORTF introduced four new projects in FY 2023 under Goal 4.

One new project will link refugee service utilization data with patient-level demographic and Medicaid enrollment and claims data. One project promotes the expanded collection of data to identify people with ID/DD and another the collection of more specific SDOH variables. Another project will link environmental and climate data to patient-level health data.



Explore Projects Further

The [Electronic Care \(eCare\) Plan](#) app provides clinicians with a longitudinal care plan that includes patients' prioritized health concerns, interventions, and health status captured across their multiple care settings thus improving the quality of longitudinal treatment and care plan data collected for people with MCC. Improved data quality can support both more patient-centered care coordination between a patient's multiple care providers, as well as more rigorous PCOR studies that seek to understand outcomes for people with MCC using EHR data.



Explore Project Further

Projects New in FY 2023

[Data Infrastructure Supporting Research on Refugee Medicaid Service Utilization and Outcomes* \(ACF, ASPE/HSP\)](#)

[Engaging People with Intellectual and Developmental Disabilities \(ID/DD\) to Enhance Functional Disability Representation in Point of Care Settings \(CDC/NCBDDDD\)](#)

[Expanding Climate Change and Health \(CCH\) Data Infrastructure to Advance Health Interventions: Linking Health and Environmental Data to Improve Patient and Community Health* \(NIH/NIEHS\)](#)

[Small-Area Community SDOH Data: Enhancements and Linkages to Inform Action \(AHRQ, ASPE\)](#)

Projects in Progress in FY 2023

[Childhood Obesity Data Initiative \(CODI\): Integrated Data for Patient-Centered Outcomes Research Project 2.0 \(CDC\)](#)

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

[Dataset on Intellectual and Developmental Disabilities: Linking Data to Enhance Person-Centered Outcomes Research* \(ASPE/BDHAP\)](#)

Projects Completed in FY 2023

[Data Capacity for Patient-Centered Outcomes Research through Creation of an Electronic Care Plan for People with Multiple Chronic Conditions \(AHRQ, NIH/NIDDK\)](#)

*Denotes that the project addresses more than one Strategic Plan goal.



OS-PCORTF Portfolio Accomplishments and Activities

This section features a selection of FY 2023 OS-PCORTF programmatic accomplishments and activities beyond project-specific achievements that advance data capacity for patient-centered outcomes research across the Strategic Plan goals and high-priority areas identified by HHS and its agencies.

5 Peer-Reviewed Publications

5 Reports & Briefs

1 Blog Post

1 Consortium

OS-PCORTF Strategic Plan (2020-2029)

[Understanding the Impacts of OS-PCORTF Projects on Data Capacity: An Interim Qualitative Assessment](#)²

This report presents findings from an interim qualitative assessment that examined how nine OS-PCORTF projects collectively advanced the ability of researchers to conduct patient-centered outcomes research by:

- 1) improving the quality of data;
- 2) providing more relevant, comprehensive data;
- 3) enhancing analytical resources; and
- 4) reducing barriers to data access and use.



The study team conducted a targeted review of OS-PCORTF project materials and key informant interviews with project leads and team members to gain a deeper understanding of the impact of the nine OS-PCORTF projects. This report describes the direct effects of these projects on improving PCOR researchers' ability to address questions important to patients, caregivers, clinicians, and policymakers in a more robust and rigorous manner.

Economic Outcomes

[Medical Care Special Issue: Building Data Capacity to Study Economic Outcomes for Patient-Centered Outcomes Research](#)³

This 2023 special issue of *Medical Care* discusses challenges and opportunities in building data capacity for patient-centered outcomes research on economic outcomes. Featured articles focus on the measurement, collection, and linkage of economic outcomes data for PCOR



studies. The special issue draws on themes from the symposium [Building Data Capacity to Study Economic Outcomes for Patient-Centered Outcomes Research](#),⁴ convened by the OS-PCORTF with support from the RAND Corporation in December 2022.

[Federal Data for Conducting Patient-Centered Outcomes Research on Economic Outcomes](#)⁵

Based on a 2021 OS-PCORTF white paper and inventory,⁶ this article in *Medical Care* assesses coverage and gaps in federally funded data sources across three cost domains and identifies opportunities to improve the data available for studying economic impacts in patient-centered outcomes research.

[Medicare Data Linkages for Conducting Patient-Centered Outcomes Research on Economic Outcomes](#)⁷

Based on a 2022 OS-PCORTF-sponsored white paper and data inventory⁸, this article in the 2023 special issue of *Medical Care* assesses the current landscape of federally funded survey and administrative data sources that can be linked to Medicare fee-for-service data to support patient-centered outcomes research.

Persons with Disabilities, including Individuals with Intellectual and Developmental Disabilities

[Assessing Outcomes Relevant for Patient-Centered Outcomes Research Among Adults Aged 18–64 with Disabilities and Federal Data Infrastructure Opportunities](#)^{9,10}

This report and accompanying dataset inventory identify individual-level measures for conducting patient-centered outcomes research relevant to adults aged 18–64 years with disabilities. The work identifies six broad outcome domains relevant to patient-centered outcomes research for this population:

- 1) social and community engagement;
- 2) choice and control to make decisions on social and health needs;
- 3) employment and self-sufficiency;
- 4) privacy, rights, and human security;
- 5) health-related social needs; and
- 6) health and wellbeing.

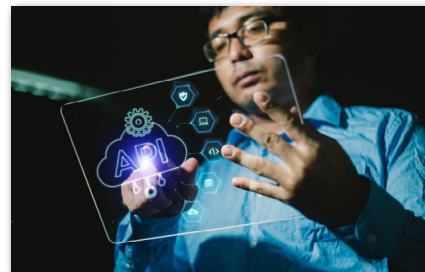
The report also assesses the literature on data infrastructure to improve the use of standardized outcome measures for adults with disabilities in PCOR studies. To facilitate patient-centered outcomes research on individual-level outcomes for adults with disabilities, efforts are needed to: 1) develop data standards to promote measure standardization across data sources, and 2) improve data collection systems and linkages. This report builds on two previous ASPE reports that identified opportunities to advance data infrastructure to enable patient-centered outcomes research for people with ID/DD through standardization, linkages, and collection of related federal data.^{11,12}



New Technologies

[Trustworthy Artificial Intelligence \(TAI\) for Patient-Centered Outcomes Research \(PCOR\)](#)¹³

This report presents the findings of an environmental scan and key informant discussions conducted to better understand the application of the six TAI principles outlined in the HHS TAI Playbook when using AI for health care research that includes patient-centered outcomes research. These six principles call for AI to be fair/impartial, transparent/explainable, responsible/accountable, robust/reliable, privacy, and safe/secure. Specifically, the findings presented in this report inform how PCOR researchers can adhere to TAI principles in three ways:



- 1) implementing considerations;
- 2) adhering to considerations for all phases of the research lifecycle; and
- 3) seizing opportunities to support improvement of tools, resources, and methods promoting adherence.

Fifteen considerations for PCOR researchers and 14 opportunities for the OS-PCORTF to advance the trustworthy use of AI in research were identified. The considerations ensure protection of patient privacy and safety as well as evaluate tradeoffs between principles.

[Synthetic Data in Health Care: A Narrative Review](#)¹⁴

This *PLOS Digital Health* journal article describes results from a literature review on the utility and potential applications of synthetic data to share health data with researchers. The authors identify seven potential uses for synthetic data in health care, including:

- 1) simulation and prediction research;
- 2) hypothesis, methods, and algorithm testing;
- 3) epidemiology/public health research;
- 4) health information technology (IT) development;
- 5) education and training;
- 6) public release of datasets; and
- 7) linking data.

The article also provides examples of publicly accessible synthetic data as well as a review of the evidence on the suitability of synthetic data for health services research. These findings show that synthetic data may help bridge common data access gaps researchers face when using data generated by real patients.

Maternal Health

Maternal Health Consortium

The ASPE-led Maternal Health Consortium brings together OS-PCORTF project leads to collaborate across projects with the common goal of improving the use of EHR data to support longitudinal maternal health research. Participating project leads represent the National Institutes of Health (NIH) National Institute of Child Health and Human Development (NICHD) and the Centers for Disease Control and Prevention (CDC) National Center for Health Statistics (NCHS). Representatives from the Office of the National Coordinator for Health Information Technology (ONC) also participate in the Consortium, which is chaired by NIH/NICHD.



[United States Core Data for Interoperability Pregnancy Status Data Element Comment](#)¹⁵

ONC sought expert input from the ASPE-led Maternal Health Consortium members on the United States Core Data for Interoperability (USCDI) Version 3 that included new Data Classes such as Health Insurance Information, Health Status, and New Patient Demographic Data Elements. Specifically, the Consortium members reviewed and provided feedback on the pregnancy status data element within the Health Status Assessment data class. As part of the feedback, the Consortium recommended adding data elements capturing birth time and fetal heart rate to the data class. It also provided input on how to best capture pregnancy-related outcomes for infants and mothers including identification of applicable standards and existing Logical Observation Identifiers Names and Codes (LOINC) codes to reference pregnancy status. The feedback from all Consortium members was compiled and submitted on April 29, 2022 for ONC consideration as the USCDI Version 3 was refined and finalized.

[MaternalHealthLink](#)¹⁶

This blog highlights one of the notable achievements of the collaboration forum created by the Maternal Health Consortium, which is testing the open-source application (app), MaternalHealthLink developed by a participating project to automate EHR data abstraction from a health information exchange for public health reporting. Specifically, MaternalHealthLink, automates processes to aggregate, calculate, and exchange patient-level EHR data using the FHIR implementation guide standard, another notable achievement, while flexibly accommodating research contexts and needs. The MaternalHealthLink [source code](#) is available on GitHub.¹⁷

[State Experiences Linking Medicaid Data with Birth Certificates and Other Data Sources](#)¹⁸

This article in *Medical Care* describes an environmental scan conducted to assess how states are linking Medicaid claims data with other maternal and child health data to study maternal and child health outcomes. The authors identify existing linkages employed by 33 jurisdictions, including Medicaid-to-birth record linkages and all-payer claims databases (APCD)-to-vital record linkages. Additionally, the authors describe data linkages and example use cases in nine states. Findings revealed challenges with supporting data linkages, including access to data and limited time, resources, and experienced staff, as well as linkage facilitators, including staff relationships and institutional buy-in.

[Linking State Medicaid Data and Birth Certificates for Maternal Health Research](#)¹⁹

This report describes work of the ASPE-led Maternal Health Consortium with state and federal partners to develop guiding principles for a standardized methodology for linking mothers' Medicaid claims data with infant birth certificate data across five states, including data storage and access. In addition, the report presents a research agenda of maternal health topics including:

- 1) impact of postpartum Medicaid expansion on outcomes and Medicaid service utilization,
- 2) changes in telehealth use during and after COVID-19, and
- 3) impact of accessing reproductive health services on maternal health and birth outcomes.

The report is the second in a series of ASPE reports²⁰ focusing on strengthening efforts to link state Medicaid data with other data sources to advance patient-centered outcomes research in maternal health.

Other Initiatives Across the Portfolio

[State All Payer Claims Databases: Identifying Challenges and Opportunities for Conducting Patient-Centered Outcomes Research and Multi-State Studies](#)²¹

This report describes findings from discussions with state officials and other stakeholders about the utility of state APCDs for PCOR analyses across states. The authors describe potential uses of APCD data for patient-centered outcomes research, such as enabling multi-state comparisons of outcomes, linking APCD data to other PCOR-relevant data to enhance longitudinal assessments of patient-centered outcomes, and improving the evidence base for small patient populations such as people with rare diseases. Barriers to using APCD data for PCOR studies include missing data on race/ethnicity and insurance, outdated Medicare data, lack of inter-state communication, infrastructure and interoperability concerning state APCDs, and lack of a national or multi-state APCD. This report is the third in a series of ASPE reports on APCDs.^{22,23}



OS-PCORTF Dissemination Activities

During FY 2023, the OS-PCORTF raised researchers' and policymakers' awareness of the portfolio's activities and impacts through several presentations at national conferences. These presentations included:

- 1) two poster presentations at Academy Health's 2023 Annual Research Meeting titled 1) "Improving Data Infrastructure for Patient-Centered Outcomes Research for People with Intellectual and Developmental Disabilities," and 2) "Medicare Data Linkages for Conducting Patient-Centered Outcomes Research on Economic Outcomes;"
- 2) a panel presentation at the 2022 American Medical Informatics Association (AMIA) Annual Symposium titled, "Federal Initiatives to Increase Access to and Linkage of Longitudinal Data Sets to Enhance Data Capacity for Patient-Centered Outcomes Research;" and
- 3) one poster at the 2022 AMIA Annual Symposium titled, "Trustworthy Artificial Intelligence in Patient-Centered Outcomes Research."





Conclusion

For over a decade, ASPE has coordinated across federal agencies and programs to build and strengthen data capacity for patient-centered outcomes research. Improving the ability to collect, link, and analyze data supports PCOR studies that generate the high-quality evidence needed to inform decisions by patients, providers, and policymakers and to improve outcomes for all Americans.

New and enhanced data infrastructure helps address national and HHS health priorities including health equity, the opioid overdose crisis, maternal mortality, and ID/DD. The OS-PCORTF portfolio produces a range of data and technical products that improve data quality, relevance, and comprehensiveness; enhance analytic resources for conducting patient-centered outcomes research; and address barriers to data access and use. Collectively, products developed through the OS-PCORTF expand data capacity across each of the four Strategic Plan goals and reflect HHS's commitment to addressing evolving data infrastructure needs during the next five years and beyond.



Appendices

Appendix A. Key Impacts of OS-PCORTF Projects Completed in FY 2023

This appendix highlights key impacts of the four Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) projects that concluded in Fiscal Year (FY) 2023.

AMNET: An Addiction Medicine Network to Address the United States Opioid Crisis

Challenge Addressed

Of the over two million Americans with an OUD, only about one-quarter receive treatment.²⁴ Office-based opioid treatment programs play a key role in the response to the opioid crisis, particularly in rural and underserved communities. These office-based opioid treatment programs expand access to two medications for the treatment of opioid use disorder: 1) buprenorphine, and 2) naltrexone.²⁵ However, there is a lack of standardized data on patient characteristics and outcomes for patients treated with medications for opioid use disorder (MOUD) in office-based settings. Without standardized and validated OUD and treatment data, it is difficult for researchers to conduct comparative clinical effectiveness research (CER), such as comparing different office-based treatments for opioid use disorder.

Project Goal and Objectives

The overall goal of this project was to establish a practice-based research network and electronic patient registry, called Addiction Medicine Practice Based Network (AMNet), to collect standardized treatment and outcomes data, including clinical and patient-reported outcome measures (PROMs). The project leveraged PsychPRO, the American Psychiatric Association's national mental health data registry. The project objectives were to:

- Establish AMNet, an addiction medicine practice-based research network.
- Adapt PsychPRO to support data collected for AMNet.
- Perform feasibility and validity testing of AMNet measures and OUD common data elements.
- Expand addiction medicine research capacity and outreach through AMNet participant training and related dissemination activities.

Project Impact on Expanding Data Capacity for Patient-Centered Outcomes Research

With funds administered by the NIH/National Institute on Drug Abuse (NIDA), the Friends Research Institute, the American Psychiatric Association, and the American Society for Addiction Medicine worked collaboratively to establish AMNet. AMNet provides more comprehensive data for clinical and health services research related to addiction. AMNet collects and aggregates standardized clinical data from participating addiction medicine practitioners and integrates that data into a clinical data registry adapted from PsychPRO. AMNet currently consists of a network of 141 providers across 15 practices.

AMNet improves clinician, researcher, and other stakeholder access to real-time clinical and patient-reported OUD data to improve surveillance and clinical decision-making among treatment providers. AMNet aggregates and standardizes a range of data, including PROMs, MOUD treatment and recovery service utilization, OUD patient outcomes, and quality measures, providing researchers access to more comprehensive, relevant data for patient-centered outcomes research. Additionally, AMNet provides access to various assessment measures (e.g., Patient-Reported Outcomes Measurement Information System® Pain Interference Instrument-Adult Short form) as well as quality measures (e.g., patient adherence to OUD pharmacotherapy, percent of patients who completed follow-up visits) that can be used to aid performance and quality improvement efforts and research on patient-centered outcomes. Additionally, the project enhanced analytic resources by conducting real-world testing of the AMNet platform to understand strengths and limitations of the platform for data collection and analysis. This testing identified opportunities to improve EHR integration, user interface design, and patient engagement, which can inform future efforts.

Key Products and Final Report



Addiction Medicine Practice Based Network (AMNet). AMNet is a practice-based research network and electronic patient registry platform designed to collect standardized treatment and outcomes data for clinical and health services research related to addiction.²⁶ Providers interested in joining AMNet to access the registry can complete a five-minute survey to determine their eligibility.



Addiction Medicine Practice-Based Research Network (AMNet): Building Partnerships. This column published in *Psychiatric Services* describes the project’s collaborative efforts with the American Psychiatric Association, American Society of Addiction Medicine, Friends Research Institute, and NIH/NIDA to create AMNet.²⁷



Addiction Medicine Practice-Based Research Network (AMNet): Assessment Tools and Quality Measures. This article published in *Substance Abuse and Rehabilitation* summarizes the results of an environmental scan and efforts to identify, review, and select 12 PROMS and three quality measures related to OUD and SUD for inclusion in AMNet.²⁸ An accompanying toolkit describing the PROMs available within AMNet is available on AMNet’s website.²⁹



Beta Testing of AMNet Measures. To ensure data quality, the NIH/NIDA team tested the feasibility and validity of AMNet data elements in one of the clinical registries as well as the clinical utility and feasibility of deploying AMNet measures into addiction practice settings. The NIH/NIDA team conducted interviews with practitioners to understand the impact of AMNet on workflow and clinician burden. A manuscript describing quantitative and qualitative results of this testing is currently under review by the *Journal of Drug Issues*.



Final Project Report. A final report, to be made available on [ASPE’s website](#), summarizes critical background information, major project accomplishments, lessons learned, and key products and publications resulting from project activities.

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NIH/NIDA

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Project Profile
[ASPE Website Project Profile](#)

Strategic Plan
Goals Addressed



Goal 1: Data Capacity for National Health Priorities

Data Capacity for Patient-Centered Outcomes Research through Creation of an Electronic Care Plan for People with Multiple Chronic Conditions

Challenge Addressed

At least one in four people in the U.S. lives with two or more chronic conditions.³⁰ These individuals’ complex health needs are often cared for by multiple providers leading to fragmented care as electronic health information often resides across multiple settings of care. As a result, clinicians, patients, and their caregivers may need to navigate multiple care plans. To support more efficient and effective coordination of care for people living with multiple chronic conditions (MCC), providers need to be able to share data across health care organizations and different electronic health records (EHRs). However, interoperability and exchange of data across different EHRs are limited, making it difficult to compile patient data across settings that is needed to support care coordination, track patient progress toward goals, and study outcomes meaningful to patients.

Project Goal and Objectives

An electronic care plan (eCare Plan) is one strategy to address the data challenges described above by providing an EHR-accessible consolidated and centralized care plan available to the patient, their caregivers, and each of the patient's care providers. This project aimed to build data capacity for pragmatic patient-centered outcomes research by developing the interoperable eCare Plan standards and application (app) to extract, aggregate, exchange, and visualize disparate EHR and patient-reported data across settings. The objectives of the project were to:

- Expand an existing data element and standards set focused on chronic kidney disease to include three co-morbid health conditions: cardiovascular disease, opioid use disorder (OUD), and diabetes.
- Develop a clinician-facing open-source, SMART on FHIR® eCare Plan app for people with MCC and an accompanying Health Level Seven (HL7®) FHIR® implementation guide and test the app and implementation guide in populations with chronic kidney disease.
- Establish an eCare Plan repository and app development collaborative to support the project's development, testing, piloting, and implementation efforts, and provide an open-source repository available to enable searching for, access to, and sharing and exchange of eCare Plans.
- Disseminate all project products through free, open-source channels (e.g., federal government websites, open-source software exchanges such as GitHub or the HL7 Confluence wiki).

Project Impact on Expanding Data Capacity for Patient-Centered Outcomes Research

The Agency for Healthcare Research and Quality (AHRQ) and the National Institutes of Health (NIH) National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) clinician-facing eCare Plan app is designed to improve the quality of point-of-care data for people with MCC. The eCare Plan app provides clinicians with a longitudinal care plan that includes patients' prioritized health concerns, goals, preferences, interventions, and health status captured across their multiple care settings. By defining, organizing, and standardizing patient-reported and EHR data from various sources into a single eCare Plan, the project enables data sharing across different settings (i.e., home, community, health care, and research) using different EHRs³¹ to support patient-centered care coordination. Compared to individual, siloed care plans, this eCare Plan enhances the completeness, accuracy, and consistency of patient data available for pragmatic PCOR studies.

The project also produced enhanced analytic resources that build data infrastructure for PCOR studies for people with MCCs. The PCOR community can adapt the eCare Plan app's open-source code to build a version of the app suitable for different use cases. Researchers can leverage the existing standardized disease data elements and value sets to extract and aggregate EHR and patient-reported data to produce more comprehensive PCOR datasets and can modify these resources as needed to fit their study aims. Additionally, the implementation guide enables researchers and health care organizations to implement the FHIR standards in their own settings to support data extraction and interoperability.

The products have already been utilized by researchers as well as standards development organizations.

- NIH's National Institute on Aging has funded an R01 grant project that has built on the eCare Plan. The project called CARESync aims to identify older adults at risk for adverse outcomes when hospitalized and improve transitions from hospital to home.
- The Health Information Technology for Economic and Clinical Health's (HITECH's) Interoperability Standards Work Group (ISWG) recommended ONC include a new Care Plan data class in the United States Core Data for Interoperability (USCDI) with the following set of data elements: Care Plan Information, Assessment, Health Concerns, Goals, Interventions, and Outcomes/Evaluation. Using the eCare Plan as an example, the ISWG noted that the Care Plan is a structured package of core data elements that serves as a blueprint shared by all care team members to guide the patient's care. In April 2024, the Health Information Technology Advisory Committee (HITAC) voted unanimously to add a Care Plan data class to USCDI Version 5.³² NIH, AHRQ, and the Centers for Medicare & Medicaid Services worked in partnership to develop the recommended data standards.
- Finally, as value sets play a crucial role in clinical research, quality measures reporting, and clinical decision support rules, the ONC Applications of Machine Learning to Health Data for Patient-Centered COVID-19 Research project,

is utilizing COVID-19 value sets developed through the eCare Plan project. These value sets, applied using Clinical Quality Language (CQL) logic, help identify patient cohorts for answering critical research questions. An example of a research question is determining the likelihood of adverse health conditions developing in patients diagnosed with COVID-19 by using a split learning model. A positive outcome from this analysis could aid in care planning for individuals who have recovered from COVID-19 but are at risk of adverse health outcomes due to their infection.

Key Products and Final Report



eCare Plan Project Website. AHRQ supports a collaborative project website to share meeting materials, project documents, presentations, and deliverables.³³



Comprehensive MCC Data Elements and Standards Set. This spreadsheet documents data elements, attributes, value sets, and FHIR mappings identified by the eCare Plan team for chronic kidney disease, chronic pain, type 2 diabetes, and cardiovascular disease. It enables standardized exchange of data for these conditions across health settings.³⁴



MCC eCare Plan Clinician-Facing App. The code for the clinician-facing SMART on FHIR eCare Plan app is fully accessible online through GitHub.³⁵



eCare Plan HL7® FHIR® Implementation Guide. The implementation guide for the clinician-facing eCare Plan app defines how to represent coded content (e.g., value sets) used to support the care planning activities for patients living with MCC. The implementation guide for the chronic disease value set is currently undergoing ballot testing; formal HL7 publication of the implementation guide is anticipated in May 2024.³⁶



Final Project Report. This report documents the usability testing and evaluation results from pilot testing the eCare Plan app, including lessons learned and recommended app updates.³⁷

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Project Profile
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Strategic Plan
Goals Addressed



Goal 4: Person-Centeredness, Inclusion, and Equity

Enhancing Identification of Opioid-Involved Health Outcomes Using Linked Hospital Care and Mortality Data

Challenge Addressed

In the U.S., deaths from an opioid overdose increased more than six times between 1999 and 2021.³⁸ PCOR researchers need comprehensive national-level data on opioid-related emergency department visits, hospitalizations, and deaths to develop strategies to reduce morbidity and mortality from the misuse and overdose of opioids. When this project began in 2018, nationally representative statistics on opioid-involved hospitalizations were limited and often incomplete.

The Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), houses three data sources that researchers can use to study hospital care and deaths related to opioid-involved drug overdose: 1) the National Hospital Care Survey (NHCS), 2) the National Death Index (NDI), and 3) the National Vital Statistics System restricted-use Drug-Involved Mortality files (DIM). Separately, each data source has limitations for surveillance of the opioid epidemic. The NHCS is limited in the data needed to identify specific opioids (e.g., fentanyl) involved in a clinical encounter because the algorithms used to identify specific opioid agents are limited to diagnosis and procedure codes. In addition, the NHCS does not include deaths that occurred outside a hospital setting. Identifying these deaths requires linkage to other data sources such as the NDI. Finally, while the DIM file contains data on specific opioid agents, these data are obtained solely from the literal text on death certificate records, which can vary based on the heterogeneity of death investigation practices and capacities for collecting drug information at the time of death (e.g., toxicology and autopsy).

Project Goal and Objectives

The overall goal of this project was to improve surveillance and expand researchers' access to data on hospital care patterns and risk factors associated with opioid overdose deaths. The project objectives were to:

- Create a dataset for research by linking hospital care and mortality data by merging the NHCS, NDI, and DIM and analyze this dataset to explore characteristics of individuals who had opioid-related events, patterns of hospital use in months prior to death, and comparisons of patients and services.
- Improve researchers' ability to identify opioid-specific hospital encounters and deaths by improving existing techniques and developing new methods in vocabulary and procedure coding.
- Enrich the opioid-specific hospital care data available in the linked NHCS, NDI, and DIM dataset with enhanced hospital and death certificate opioid identification.
- Invest in the infrastructure to improve the collection and reporting of hospital data as well as disseminate the methodologies, analyses, and knowledge obtained to promote the use of the enhanced dataset for patient-centered outcomes research.

Project Impact on Expanding Data Capacity for Patient-Centered Outcomes Research

The CDC/NCHS team improved the comprehensiveness of data on opioid-related hospital care and overdose deaths by creating two new datasets that link death certificate information from the DIM file with data from the 2014 and 2016 NHCS and NDI. As a result, researchers can compare the characteristics of patients who experience an opioid-related hospitalization and identify patterns of hospital use for patients who died of an opioid overdose. The development of the linked datasets showed the importance of collecting personally identifiable information in the NHCS, which supported data linkage to the NDI. Linking the NHCS and NDI enabled inclusion of information from the DIM, which provided data on the specific drugs involved in overdose deaths for patients who utilized a hospital for treatment prior to their death.

In addition to improving the comprehensiveness of the data, the CDC/NCHS team also enhanced the analytic resources available to researchers to better understand the opioid crisis. The team developed the Enhanced Opioid-Identification Algorithm, which was used to identify opioid-involvement and overdose encounters in unstructured clinical notes that otherwise would not have been identified using medical codes alone, thus highlighting the advantage of collecting EHR data as part of the NHCS. The CDC/NCHS team also used the Enhanced Opioid-Identification Algorithm to inform development of another algorithm for identifying opioid involvement with co-occurring substance use disorders (SUD) and mental health issues (MHI), thus improving the variables available to study morbidity and mortality for patients with these co-occurring disorders.

Key Products and Final Report



2014 NHCS Data Linked to the 2014-2015 National Death Index (NDI) Linked to the 2014-2015 Drug-Involved Mortality (DIM) Data Report. This report describes the three source datasets and provides additional resources on the linkage. The linked data file contains over 5,000 NHCS records in which cause of death involved an opioid and can be accessed by submitting an application to the CDC Research Data Center.³⁹



The Linkage of the 2014 National Hospital Care Survey to the 2014/2015 National Death Index: Methodology Overview and Analytic Considerations. This report describes the process used to link the 2014 NHCS and the 2014/2015 NDI data and includes a brief overview of the data sources, a description of the methods used for linkage, and analytic guidance for researchers.⁴⁰



2016 NHCS Data with Enhanced Opioid-Identification Linked to the 2016-2017 National Death Index (NDI) Linked to the 2016-2017 Drug-Involved Mortality (DIM) Data Report. This report describes the three source datasets, provides information about the 2016 NHCS-enhanced opioid identification variables, and provides additional resources on the linkages. The linked data file contains over 9,500 NHCS records in which cause of death involved an opioid and can be accessed by submitting an application to the Research Data Center.⁴¹



Enhanced Opioid Identification Algorithm Methodology Report. This report summarizes the development of techniques to identify opioids in the 2016 hospital and death certificate data.⁴²



Annual Hospital Report Portal. The portal allows hospitals participating in the NHCS to customize site-specific dashboards to view statistics on discharges, patient and visit characteristics, and mortality. A demonstration version of the portal is available here.⁴³



Four NCHS Reports. The project's publications include reports utilizing the enhanced algorithm and merged datasets to analyze opioid-involved emergency department visits, hospitalizations, and deaths.^{44,45,46,47}



Final Project Report. The final report summarizes critical background information, major project accomplishments, lessons learned, and key products and publications resulting from project activities.⁴⁸

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Strategic Plan
Goals Addressed



Goal 1: National Health Priorities



Goal 2: Data Standards and Linkages
for Longitudinal Research

Surveillance Network: Maternal, Infant, and Child Health Outcomes Following Treatment of Opioid Use Disorder (OUD) During Pregnancy

Challenge Addressed

From 1999-2014, the prevalence of OUD among pregnant women in the U.S. quadrupled from 1.5 to 6.5 per 1,000 delivery hospitalizations.⁴⁹ Untreated OUD during pregnancy increases the risk of an infant born with neonatal abstinence syndrome and other serious health outcomes, such as development delays. The American College of Obstetricians and Gynecologists recommends that pregnant people with OUD be offered MOUD, such as methadone and buprenorphine.⁵⁰ However, limited data are available to compare the risks and benefits of different medication treatment regimens and the long-term health outcomes of children who were prenatally exposed to opioids or MOUD.

Project Goal and Objectives

The overall goal of this project was to establish a surveillance network to collect data on maternal, infant, and child health outcomes associated with treatments for OUD during pregnancy. The overall objectives of the project were to:

- Establish an organizational structure, inclusive of federal agency representatives, clinical and public health partners, and the project's CDC Steering Committee, to provide critical input on linked maternal and infant health data collection approaches and analytical priorities.
- Develop a data platform—the MATernal and Infant Network to Understand Outcomes Associated with Medication for Opioid Use Disorder during Pregnancy (MAT-LINK)—to collect linked maternal and infant data among women treated for OUD during pregnancy.
- Analyze and disseminate preliminary results of MAT-LINK's development and the use of aggregated data submitted by participating MAT-LINK clinical sites to inform patient-centered care for pregnant women with OUD and for infants and children with prenatal opioid exposure.

Project Impact on Expanding Data Capacity for Patient-Centered Outcomes Research

According to the project leads at the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD), MAT-LINK is the first surveillance system to collect comprehensive, longitudinal EHR data to monitor maternal, infant, and child health outcomes associated with MOUD during pregnancy. MAT-LINK created a data platform to collect and standardize EHR data from an initial cohort of four geographically diverse clinical sites across the U.S. The dataset includes over 2,000 linked mother-infant pairs with OUD, with child follow up through age two. Researchers can use this dataset to study the effects of different MOUD regimens on infant and child development and to understand the role of mediating and moderating factors (including polysubstance use, maternal comorbidities, and other psychosocial factors) on maternal and infant outcomes. Evidence about the impacts of MOUD during pregnancy enhances informed decision-making, allowing patients to make decisions based on what they feel is best for their baby, clinicians to deliver person-centered care informed by evidence on treatment options and outcomes, and policymakers to improve efforts to address the opioid epidemic.

The CDC team also developed tools to address data quality issues when creating the MAT-LINK platform. The team developed methods to collect both abstracted (manually submitted data from clinical sites) and extracted (data queried from the participating clinical sites) data, which improved the consistent and efficient collection of data across sites and contributed to a higher quality dataset. This approach to EHR data collection and interoperability was recognized as an innovative process for improving data comprehensiveness and data quality; In 2022, MAT-LINK received the Information Technology award from the CDC NCBDDD for data pipelining, optimization, and transformation.

In 2020, the OS-PCORTF-funded [MAT-LINK2: Expansion of MATernal and Infant Network to Understand Outcomes Associated with Treatment for Opioid Use Disorder during Pregnancy](#) to scale the project to three additional clinical sites representing varied geographic, racial, ethnic, and socioeconomic populations which expanded the dataset from over 2,000 to over 5,000 linked pregnant person-infant pairs with OUD. MAT-LINK2 also extends follow-up data collection

for children from two years through six years of age. Due to the success of MAT-LINK, the MAT-LINK team obtained additional CDC funding to grow MAT-LINK in 2023 from 7 to 11 clinical sites and to expand the MAT-LINK cohort to also include polysubstance use and cytomegalovirus.

Key Products and Final Report



MAT-LINK Project Website. The CDC NCBDDD hosts the MAT-LINK project website, which describes the clinical and surveillance needs for the project, information on the data sample, project outcomes, and relevant resources.⁵¹



MAT-LINK Data and User Guide. This site includes information on how to request the restricted data and user guide, including the Proposal Form.⁵²



Core Set of Variables. This article in the *Journal of Women's Health* provides a list of the core variables used in the surveillance of OUD during pregnancy. The data elements cover maternal health history, pregnancy and postpartum outcomes, maternal delivery and neonatal birth outcomes, and child health history.⁵³



The MATernal and Infant Network MAT-LINK to Understand Outcomes Associated with Treatment of OUD During Pregnancy (MAT-LINK): Surveillance Opportunity. This publication in the *Journal of Women's Health* discusses how MAT-LINK addresses knowledge gaps regarding the treatment of OUD during pregnancy. It describes MOUD options and the known pregnancy and infant outcomes associated with these treatments.⁵⁴



Polysubstance Use in Pregnancy: Surveillance, Interventions, and Next Steps. This publication in the *Journal of Women's Health* describes the activities of the CDC/NCBDDD team to address adverse maternal and child health outcomes from polysubstance use and gaps related to surveillance, routine screening, and prevention of polysubstance use during pregnancy.⁵⁵



Medication for Opioid Use Disorder During Pregnancy — Maternal and Infant Network to Understand Outcomes Associated with Use of Medication for Opioid Use Disorder During Pregnancy (MAT-LINK), 2014–2021. This publication in the *Morbidity and Mortality Weekly Report Surveillance Summaries* describes MAT-LINK surveillance and data methods.⁵⁶



Three Journal Article Manuscripts. The team currently has two manuscripts under CDC clearance review, and a third manuscript that will soon undergo clearance review. The articles describe findings on trends in MOUD-related health outcomes and service utilization using MAT-LINK data.^{57,58,59}



Final Project Report. This final report summarizes the background, lessons learned, future considerations, and products and presentations resulting from the MAT-LINK project.⁶⁰

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[ASPE Website Project Profile](#)

Strategic Plan
Goals Addressed



Goal 1: Data Capacity for National Health Priorities



Goal 2: Data Standards and Linkages for Longitudinal Research

Appendix B. New Projects Funded in FY 2023

This appendix provides an overview of the 12 new Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) projects funded in Fiscal Year (FY) 2023.

Capturing the Full Trajectory of Patient-Centered Cancer Care Via Enhanced Data Linkages

Cancer is a significant cause of morbidity and the second leading cause of mortality in the U.S.⁶¹ Cancer researchers use electronic health record (EHR) and cancer registry data to study the comparative effectiveness of cancer treatments on patient outcomes. However, data on patient demographics, medical history, cancer diagnoses, treatments, treatment variations, and outcomes are often incomplete or unavailable within a single data source.

To improve researchers' access to comprehensive data to study the full course of cancer patients' care, this National Institutes of Health (NIH) National Cancer Institute (NCI) project will link Surveillance, Epidemiology, and End Results (SEER) cancer registry data with EHR data from the NIH National Center for Advancing Translational Sciences (NCATS) National COVID Cohort Collaborative (N3C). Researchers will be able to use the linked dataset, called N3C Cancer Enclave, to characterize variations in cancer treatments and study the impact of treatment variations on patient outcomes other than mortality. The project team will evaluate the capability of the linked dataset to address patient-centered outcomes research for one common (e.g., breast, lung, prostate, or colorectal) and one rare (e.g., a leukemia or lymphoma) cancer.

Implementing Agency

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[ASPE Website Project Profile](#)

Strategic Plan Goals Addressed



Goal 1: Data Capacity for National Health Priorities



Goal 2: Data Standards and Linkages for Longitudinal Research

Code Map Services for Interoperability of Common Data Models and Data Standards

Researchers use common data models (CDMs) to standardize data generated outside of clinical trials (i.e., real-world data derived from a variety of sources) for comparative clinical effectiveness research (CER). CDMs provide a defined structure, format, and terminology for such real-world data that enables the interoperability and consistency of data from different sources, thereby increasing the data's analytic power. Several CDMs exist (e.g., Observational Medical Outcomes Partnership [OMOP], Sentinel, PCORnet, Informatics for Integrating Biology and the Bedside [i2b2]/Accrual Trials Network [ACT], and TriNetX) to support standardized data for conducting multicenter studies. Each CDM acts as its own language with its own standardized formats, and many research networks use data harmonized to only one CDM for research. Further, these CDMs are not currently interoperable, requiring researchers who wish to combine data from sources that use different CDMs to transform data standardized in one CDM to another. These CDM mappings are not only time-consuming to produce but are often study-specific and not validated, so they cannot be leveraged by other researchers. This lack of interoperability inhibits potential research collaborations using data across sites or research networks.

To address this challenge and improve researchers' access to more comprehensive real-world data for patient-centered outcomes research, this NIH/NCATS project, with support from the U.S. Food and Drug Administration (FDA) and NIH/NCI, will create an automated tool—called Code Map Services—that will transform data stored in one CDM format into another (e.g., data collected and stored in OMOP could be translated into Sentinel). The Code Map Services will establish

a source of truth within a sustainable ongoing government supported infrastructure, NCI's Cancer Data Standards Registry and Repository (caDSR II) and enable direct submission of clinical trials data from any CDM to the FDA. Building on a prior OS-PCORTF project, [Harmonization of Various Common Data Models and Open Standards for Evidence Generation](#), Code Map Services will use open-source, consensus-based standards to create the CDM mappings for five common CDMs: OMOP, Sentinel, PCORnet, i2b2/ACT, and TriNetX. The Code Map Services will be publicly available to researchers through caDSR II. The services will enable more efficient cross-network and cross-CDM data sharing, ultimately improving the availability of standardized data for PCOR studies across a range of patient populations and settings. The tool will also decrease duplicative efforts to repeat CDM-to-CDM mappings between models registered in caDSR II.

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**Strategic Plan
Goals Addressed**

Goal 2: Data Standards and Linkages
for Longitudinal Research



Goal 3: Technology Solutions to
Advance Research

Compendium of Policies on Use of Linkable Mortality Data for PCOR in the Nation's 57 Mortality-Reporting Jurisdictions

Mortality and survival data are essential for patient-centered outcomes research on preserving and extending life. These data are particularly important given rising mortality rates associated with COVID-19, suicide, and overdose and the recognition that mortality risk can be influenced by social, physical, and economic environments. However, gaining access to mortality data is challenging because these data are owned by 57 separate state and territory jurisdictions, each with their own policies (i.e., laws and regulations) on accessing and using the data for patient-centered outcomes research. These policies vary considerably and there is no single source of information on each jurisdiction's data access and use requirements. Furthermore, access to the two national systems for mortality data with individual identifiers to support data linkages—the National Death Index (NDI) and the Social Security Death Master File (DMF)—is often determined by the most restrictive jurisdiction's policy. As a result, researchers can spend considerable time and resources determining whether linkable mortality data are available for their studies.

To improve the usability of national datasets and reduce barriers to data access and use, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) Office of Behavioral Health, Disability, and Aging Policy (BHDAP) will produce a systematic inventory and database of the policies on the use of linkable mortality data for patient-centered outcomes research within all 57 mortality-reporting jurisdictions. The resulting database will describe: 1) data use policies (e.g., data protection requirements, permitted uses of research data, requirements for legal, ethics, or privacy review); and 2) data access requirements (e.g., point of contact, application process, fee schedule). This inventory and database will improve the efficiency of accessing data for research by increasing transparency around data governance policies, making it easier and less expensive for researchers to determine which data are available to examine patterns and predictors of patient survival and mortality, and how to access those data.

Implementing Agency

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Strategic Plan
Goals AddressedGoal 2: Data Standards and Linkages
for Longitudinal Research

Data Infrastructure Supporting Research on Refugee Medicaid Service Utilization and Outcomes

The U.S. refugee resettlement program has welcomed over three million people since the 1970s. The Administration for Children and Families (ACF) Office of Refugee Resettlement offers a range of services through the refugee resettlement program, and an estimated 60 percent of recently arrived refugees are covered by Medicaid. Understanding and improving the services provided to refugees requires access to data on health outcomes, health care utilization, and social determinants of health (SDOH). However, the availability of these data is limited, which makes it difficult for researchers to study the impact of these programs on the health and wellbeing of refugee populations.

To address this gap and improve the availability of relevant data for PCOR studies, this ACF project will link data from the Office of Refugee Arrivals Data System, which contains information on refugee demographics and service utilization, to the Centers for Medicare & Medicaid Services (CMS) Transformed Medicaid Statistical Information System (T-MSIS), which contains data on Medicaid enrollment and claims. The new linked dataset will enable researchers to assess the effects of policies and programs that aim to increase access to and quality of health care on outcomes such as maternal and infant health, and long-term health. The dataset will also support researchers in addressing PCOR questions about the effectiveness of interventions on increasing access to preventive care. The project will evaluate the quality of the linkage of these two datasets, which will produce learnings for other researchers regarding the strengths and limitations of linking data that lack Social Security numbers, a common identifier used for linking.

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Project Profile

[ASPE Website Project Profile](#)Strategic Plan
Goals AddressedGoal 2: Data Standards and Linkages
for Longitudinal ResearchGoal 4: Person-Centeredness, Inclusion,
and Equity

Engaging People with Intellectual and Developmental Disabilities to Enhance Functional Disability Representation in Point of Care Settings

People with intellectual and developmental disabilities (ID/DD) experience systemic inequities in health care access, morbidity, and mortality compared to people without ID/DD. To identify and address inequities faced by the ID/DD population, researchers and public health professionals need access to standardized health care and service data with consistent identification and representation of people with ID/DD. There are many challenges to accessing this information in clinical data, however, including the heterogeneity of ID/DD, the many diagnosable conditions that may be associated with ID/DD, variable disability data collection practices at the point of care, and the wide ranging functional limitations and abilities for performing activities of daily living among people with ID/DD. As a result, researchers mostly rely on diagnostic codes captured in the EHR to identify people with ID/DD, which may not be representative (e.g., may exclude functional limitations).

To address these challenges and improve the quality of demographic data on people with ID/DD from clinical records, this Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD) project aims to develop a functional disability demographic checklist with input from adults with ID/DD for use at the point of care. The checklist is designed for use in clinical settings and will consist of a minimum set of

questions that leverages and adapts existing survey questions from the American Community Survey and the Washington Group Short Set on Functioning to identify people with ID/DD. CDC NCBDDD will also evaluate the use of the new data collection checklist in a feasibility pilot. By facilitating the standardized assessment and capture of ID/DD status as demographic data at the point of care, this checklist has the potential to increase identification and representation of people with ID/DD in both clinical and health care administrative datasets used for CER. In turn, this may strengthen capacity to study health outcomes associated with services, supports, and interventions designed to improve the health and wellbeing of people with ID/DD.

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Strategic Plan Goals Addressed



Goal 4: Person-Centeredness, Inclusion, and Equity

Expanding Climate Change and Health Data Infrastructure to Advance Health Interventions: Linking Health and Environmental Data to Improve Patient and Community Health

Intensified weather patterns and natural disasters due to climate change directly and indirectly impact human health and safety, with vulnerable populations bearing disproportionate burden. To understand and address environmental risks to human health from climate-related events, researchers and policymakers need access to timely, interoperable, and linkable environmental, climate, and health data. However, such data currently exist in siloed repositories, are collected and used for differing purposes, and have varied access and use requirements. This limits the availability and comparability of data to research the health effects of climate change, create and evaluate evidence-based interventions to protect communities, and anticipate and respond to potential adverse health outcomes resulting from these events.

To address these challenges and improve the availability of linkable environmental (and other) exposure and health outcomes data for patient-centered outcomes research, this NIH National Institute of Environmental Health Sciences (NIEHS) project will build infrastructure for a unified Findable, Accessible, Interoperable, Reusable, and Computable (FAIR+) and sustainable data ecosystem through curation, creation, and evaluation of data sources, methods, tools, and other resources. The project will curate a publicly accessible web-based catalog of available environmental and climate data sources, existing tools, methods, and educational resources to facilitate data linkages. It will create standardized datasets linking environment and climate data to patient data such as SDOH and health information (e.g., birth records, emergency department records, medication usage, and mortality). Additionally, the project will enhance analytic resources for PCOR researchers through the development of a toolkit that includes software code, libraries, data processing and analysis pipelines, and other artifacts to support additional linkages of patient-level data to climate data. The resulting products will support evidence generation about the impact of climate change and related natural disasters on health and the interventions needed to improve health outcomes.

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Strategic Plan Goals Addressed



Goal 2: Data Standards and Linkages for Longitudinal Research



Goal 4: Person-Centeredness, Inclusion, and Equity

Improving Quality of Care & Outcomes Data for Pregnant Medicaid Beneficiaries & Newborn Infants

Medicaid pays for approximately 40 percent of all births in the U.S., providing useful administrative data such as service utilization and demographics.⁶² To generate actionable evidence to improve maternal and infant health, researchers must be able to link maternal and infant records. Additionally, researchers need access to data that link maternal clinical characteristics, such as pregnancy history and risk factors, and health care outcomes data with maternal and infant Medicaid service utilization data. However, while T-MSIS claims data include information on enrollment, demographics, service utilization, and payments, the data do not sufficiently capture clinical measures relevant to maternal and infant health outcomes, such as birth outcomes or the timing and completeness of prenatal care.

To address this challenge and provide more comprehensive data on maternal and infant service utilization and outcomes, this CMS project will link Vital Records birth certificates for Medicaid-covered pregnancies and births with data on mothers and infants from T-MSIS claims data from 2016-2020. The resulting linked dataset will be accessible to researchers as a supplemental T-MISIS Analytic File. The supplemental dataset will include new clinical and demographic data elements obtained from Vital Records birth certificate data. By combining service utilization and outcome data in this linked dataset, this project will improve researchers' ability to examine the effectiveness of health care services received during pregnancy on the health outcomes of mothers and infants.

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Strategic Plan
Goals Addressed



Goal 1: Data Capacity for National Health Priorities



Goal 2: Data Standards and Linkages for Longitudinal Research



Goal 4: Person-Centeredness, Inclusion, and Equity

Linking Federally Qualified Health Center EHR and Medicaid Data for Increased Data Capacity to Understand Maternal Health Care

Federally Qualified Health Centers (FQHCs) provide many maternal health visits covered by Medicaid, presenting a unique opportunity to address adverse maternal health outcomes and optimize care among vulnerable communities. However, there is a gap in available clinical data to understand maternal health clinical practices and outcomes for FQHC patients covered by Medicaid. Currently, the CDC National Center for Health Statistics (NCHS) National Ambulatory Medical Care Survey (NAMCS) is the only source of nationally representative visit-level utilization data on ambulatory health care services provided by hospital emergency departments, outpatient departments, and ambulatory surgery locations. In 2021, NAMCS began collecting clinical visit data from FQHCs through direct EHR data transmission from FQHCs to NCHS. This NCHS project builds on another ongoing OS-PCORTF project implemented by the CDC, [Enhancing Surveillance of Maternal Health Clinical Practices and Outcomes with FQHCs' Electronic Health Records Visit Data](#), which links the 2021 NAMCS with FQHC maternal health visit data from the EHR. However, the 2021 NAMCS FQHC maternal health EHR data does not contain Medicaid data needed to understand the relationship between Medicaid coverage and maternal health visit outcomes.

To address this challenge and provide more comprehensive data for the analysis of maternal health care provided at FQHCs, this project will link the 2021 NAMCS FQHC maternal health EHR data with 2020-2021 T-MSIS claims data. This new linked dataset will enhance researchers' ability to conduct patient-centered outcomes research on maternal health care provided at FQHCs and understand health disparities among this population. Further, this dataset will allow insight

into the relationships among patient characteristics, health care services utilization, and outcomes for these maternal health visits. Researchers will be able to use these data to study differences among those with and without Medicaid as the primary source of payment.

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Goal 1: Data Capacity for National Health Priorities



Goal 2: Data Standards and Linkages for Longitudinal Research



Goal 4: Person-Centeredness, Inclusion, and Equity

Linking the National Survey of Children’s Health Longitudinal Cohort and Medicaid Claims Data to Explore Pediatric COVID-19

Since the start of the COVID-19 pandemic, more than 14 million children in the U.S. have tested positive for COVID-19.⁶³ However, a comprehensive understanding of the effects of COVID-19 infections and Long COVID in the pediatric population is lacking. Insight is needed into how health outcomes (e.g., the trajectory of children’s wellbeing, causal pathways of risk and protective factors, and the effectiveness of health care services) differ among children with Long COVID compared to other children. Research is limited due to a lack of data sources that provide the full context for patients’ COVID-19 infections and trajectories, including health service utilization, pediatric outcomes, SDOH, and family and community experiences.

To address the gap and provide more comprehensive data for pediatric COVID-19 studies, this Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) project will link data from the 2023 National Survey of Children’s Health Longitudinal Cohort (NSCH-LC) Study to T-MSIS claims data. The resulting dataset will link data on pre- and post-pandemic pediatric patient outcomes, procedures, and diagnoses from Medicaid claims with data on sociodemographic characteristics, SDOH, family and community context, barriers to health care access, and behavioral health and wellbeing from the NSCH-LC. The linked data file will enable researchers to study disparities in pediatric patient-centered COVID-19 outcomes associated with health services, supports, and interventions.

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Goal 1: Data Capacity for National Health Priorities



Goal 2: Data Standards and Linkages for Longitudinal Research



Goal 4: Person-Centeredness, Inclusion, and Equity

Panoramic View of Patient Care Through Data Innovations and Linkages

PCOR researchers use a variety of data sources (e.g., claims, EHR, and survey data) to conduct CER. The data quality and availability of each data source informs many of the PCOR questions researchers can answer. Common quality issues associated with using disparate data include lack of data standardization, lack of detailed diagnosis and procedure

information in administrative data, incomplete or missing patient-level and community-level SDOH data, and limited information about the providers delivering services. These challenges limit researchers' ability to create a comprehensive (i.e., "panoramic") view of all the health care a patient receives.

This Agency for Healthcare Research and Quality (AHRQ) project will improve the consistency and completeness of data available for comprehensively studying patient care. It will do so by standardizing, harmonizing, and de-duplicating data from disparate sources to create four publicly available state-specific encounter-level databases, the Panoramic View of Patient Care Databases. Each prototype database will improve researchers' access to more comprehensive data by linking data on the medical care patients receive in the inpatient and ambulatory care settings to health insurance enrollment information, provider characteristics, SDOH data, and community-level factors. Potential data sources include participating states' all-payer claims databases, Medicare and Medicaid claims, AHRQ's SDOH Database, and AHRQ's Physician and Physician Practice Database, as well as data from the American Hospital Association, U.S. Census Bureau, and Bureau of Labor Statistics. Researchers and policymakers will be able to use the Panoramic View of Patient Care Databases to analyze and track longitudinal health outcomes associated specific services, procedures, and treatments. The increased availability of this data to researchers can ultimately help improve understanding of the influence of individual, community, and market factors on outcomes important to patients.

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Goal 2: Data Standards and Linkages
for Longitudinal Research



Goal 4: Person-Centeredness, Inclusion,
and Equity

Small-Area Community SDOH Data: Enhancements and Linkages to Inform Action

SDOH are social, economic, and environmental factors that impact individuals' health and health outcomes, as well as overall population health and community-level health outcomes. SDOH are estimated to account for over 50 percent of the differences in county-level health outcomes and drive health disparities across counties.⁶⁴ Community or sub-county level (i.e., "small-area") SDOH data are critical for understanding and addressing community-level variation and improving health equity. However, these data are not often easily accessible in aggregate and require researchers to link multiple databases that lack standardized variables—a time and resource intensive activity.

This project builds on a prior OS-PCORTF project, [Enhancing Patient-Centered Outcomes Research \(PCOR\): Creating a National Small-Area Social Determinants of Health Data Platform](#). In the prior project, AHRQ developed the [AHRQ SDOH Database](#), which provides standardized, valid, and reliable SDOH data at the county, census tract, and ZIP code levels from 2009-2020.⁶⁵ In this new FY 2023 project, AHRQ will augment the existing SDOH database to improve the availability of more current SDOH data as well as include new SDOH data variables by: 1) including additional years of data (2021-2023) for existing variables, 2) adding new high-priority SDOH variables, and 3) identifying new data sources for inclusion that address end users' needs. Through these improvements, this project aims to enhance the availability, utility, and usability of small-area SDOH data. Researchers will be able to use the publicly available longitudinal data to conduct PCOR studies that generate evidence on the impact of SDOH at the community level.

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Goals Addressed



Goal 4: Person-Centeredness, Inclusion, and Equity

Utilizing Natural Language Processing and Machine Learning to Enhance the Identification of Stimulant and Opioid-Involved Health Outcomes in the National Hospital Care Survey

In recent years, addressing the overdose epidemic has been complicated by the growing co-use of opioids and stimulants.⁶⁶ Clinical-level data derived from the EHR can support researchers in understanding PCOR-relevant outcomes that result from stimulant-involved substance use (e.g., in-hospital mortality, transfers, and referrals). While population-level surveillance data on substance use, including opioids and stimulants, are available, there are limited national resources that capture substance use at the individual level using clinical data.

This CDC NCHS project aims to enhance analytic resources available for conducting PCOR studies on stimulant use and misuse. The project builds upon the algorithms developed by two previous OS-PCORTF-funded CDC projects: [Enhancing Identification of Opioid-Involved Health Outcomes Using Linked Hospital Care and Mortality Data](#) and [Identifying Co-Occurring Disorders among Opioid Users Using Linked Hospital Care and Mortality Data: Capstone to an Existing FY18 OS-PCORTF Project](#). These prior algorithms used machine learning and natural language processing techniques to identify opioid-involved and co-occurring substance use disorder (SUD) and mental health hospital encounters in structured and unstructured EHR data. This project will leverage a similar approach and develop a stimulant-focused algorithm. Collectively, the three algorithms will be used to identify hospital encounters involving stimulant use and co-use of stimulants and opioids in the 2020 National Hospital Care Survey (NHCS) restricted use dataset. The enhanced 2020 NHCS dataset and an accompanying aggregate results dashboard will provide researchers with comprehensive clinical data—which would otherwise be unavailable—needed to improve understanding of the effects of substance use on health outcomes.

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Goal 1: Data Capacity for National Health Priorities



Goal 3: Technology Solutions to Advance Research

Appendix C. Acknowledgements

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