Harnessing the Value of Electronic Health Record Data for Research

The United States (U.S.) faces urgent health challenges, including poor maternal and childhood health outcomes, childhood obesity, opioid use disorder, cancer, and chronic conditions, which require personalized care tailored to each patient's unique circumstances.[1] Patient-centered outcomes research (PCOR) and comparative clinical effectiveness research (CER) help identify the most effective interventions to prevent and manage complex health conditions by systematically comparing treatments and focusing on outcomes that matter most to patients, such as symptom relief and quality of life. This evidence gives patients, caregivers, and clinicians the information they need to make health choices that are safe, effective, and account for treatment benefits and risks.[2,3] PCOR and CER studies that use real-world data from electronic health records (EHRs) containing patient-reported experiences and outcomes of care strengthen the reliability of the evidence. The widespread use of EHR systems by U.S. hospitals and clinics has created a rich source of this real-world patient data that can strengthen PCOR and CER studies.[4,5]

Better EHR Data Makes it Easier to Conduct High-Quality Research

EHRs capture detailed information about patients' clinical diagnoses, treatments, comorbidities, and the care they receive. Importantly, EHRs include data from patient populations often underrepresented in traditional clinical research, making them more reflective of the populations served by the nation's health system. When combined with clinical registries and other data sources, EHR data enhances researchers' ability to deliver timely, reliable, and actionable insights to improve Americans' health. This supports more effective, patient-centered care aligned with value-based care principles.

However, gaps in the quality and accessibility of EHR data can limit the potential of PCOR and CER to generate evidence that drives better health outcomes for Americans. Inconsistent adoption of clinical content standards (e.g., for medications, laboratory orders and results, and treatments) by EHR developers and health systems leads to variability in how EHR data are captured and stored. This variability makes it difficult to collect, link, and analyze data at scale.[6] Additionally, wide variation in EHR interoperability maturity levels leads to barriers to accessing, exchanging, and combining data siloed across health systems for research.[7] Together, these challenges limit researchers' ability to generate robust evidence that can guide care decisions.[6]

The Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) coordinates across U.S. Department of Health and Human Services agencies to improve the quality, accessibility, and interoperability of EHR data for PCOR. These data infrastructure improvements support efforts to scale national research initiatives and accelerate research discoveries using real-world data. This case study highlights how OS-PCORTF projects make it easier to access, share, and use EHR data to support whole-person care for chronic and complex conditions and enable trusted person-centered research.

Interoperability

Data interoperability, also known as data liquidity, is the ability of EHRs to support the secure, efficient flow of data across organizations. Effective interoperability of health information enables care coordination among primary care clinicians and different specialists and directly impacts patient safety and the long-term health outcomes of patients managing complex conditions.[8] Allowing patient health data to flow between data silos also improves the completeness, accuracy, and overall quality of data for PCOR and CER studies that examine how different treatments and care practices affect patient outcomes.

Federal efforts, including information blocking rules,[9] United States Core Data for Interoperability (USCDI) standards,[10] the Centers for Medicare and Medicaid Services (CMS) Interoperability Framework,[11] and the Trusted Exchange Framework and Common Agreement™ (TEFCA),[12] actively promote the adoption and use of Fast Healthcare Interoperability Resources (FHIR®) and application programing interfaces (APIs) such that clinicians, patients, and researchers have the right information available to them at the right time.[13] However, despite significant national progress in improving data liquidity, adoption and implementation of data exchange standards vary. For example, lower-resourced hospitals engage less frequently in interoperable exchange compared to their higher-resourced counterparts.[14] EHR developers also implement exchange standards within EHRs differently, limiting the availability of complete and longitudinal data for PCOR and CER.

To improve data liquidity, OS-PCORTF projects have developed and tested FHIR implementation guides and FHIR-based APIs that standardize EHR data exchange for key U.S. health priorities, including pregnancy and postpartum outcomes, birth outcomes, and childhood cancer.

Pregnant and postpartum women often seek care for themselves and their babies from multiple clinicians, including obstetricians and pediatricians, which results in their health information being stored across various EHR systems. This fragmentation impedes consistent and accurate data sharing across care settings, limiting advances in maternal and infant health care and research. At the same time, the exclusion of pregnant and postpartum populations from clinical trials reduces insights into how conditions, treatments, and care practices affect outcomes. Datasets representing EHR data from across multiple systems offer a valuable opportunity to fill this gap by providing detailed, longitudinal information on pregnancy, postpartum, and early childhood outcomes.

A **National Institutes of Health (NIH)-led project** developed a suite of resources, including a **FHIR implementation guide**, **open-source measure-based software tool** called MaternalHealthLink, and API. The MaternalHealthLink tool and accompanying API extract, aggregate, and evaluate longitudinal data on maternal and infant health from EHRs to support research on maternal morbidity, mortality, and hypertensive disorders of pregnancy.

Key Impact | Accelerating Childhood Cancer and Rare Disease Research

The project tested the FHIR implementation guide and data exchange tool for a new maternal health-focused use case, within an NIH-funded pediatric research effort focused on understanding links between structural birth defects and childhood cancer.[15] Lessons learned from the pilot testing supported complete integration of the data exchange tool into the research platform. This integration now enables timelier extraction and exchange of data to support PCOR related to birth defects and childhood cancer, which can ultimately support the development of improved and targeted treatments.

Federally Qualified Health Centers (FQHCs) are safety-net settings that provide access to primary care, screening services, and prenatal care to low-income, under-insured, and uninsured individuals.[16,17] Maternal health-focused PCOR

studies that use EHR data from FQHCs have historically been limited in scope, given the relatively small number of patient encounters included in the data that were manually abstracted from a sample of FQHCs.[18] These data gaps limited the ability to accurately assess patterns of care delivery and outcomes across FQHC populations. A **U.S. Centers for Disease Control and Prevention (CDC)-led project** created an implementation guide to facilitate standards-based submission of EHR data on clinical care delivered at FQHCs to the CDC for research and public health surveillance. This approach makes it possible for FQHCs to securely send data for all maternal care to CDC for analysis, resulting in nationally representative data related to maternal health care utilization at FQHCs and post-visit outcomes (e.g., survival), which are important endpoints for PCOR and CER.

Key Impact | Improving FQHC Data Access for Maternal Health Research

The more efficient data collection process developed by the project allowed the CDC to create a nationally representative dataset from FQHCs.[18] The **2022 National Ambulatory Medical Case Survey dataset** contains data from over 5.6 million FQHC patient visits. The CDC team continued data collection producing two additional datasets: one for 2023, with over 9 million FQHC patient visits, and one for 2024, with over 10.1 million visits. Data collection will continue to support annual dataset development for 2025 and subsequent years. Additionally, the CDC team developed a regularly updated and publicly available interactive **data dashboard** based on the FQHC data, posting data within six months of submission to the CDC. Researchers can use the dashboard to create timely national estimates of medical diagnoses and maternal, respiratory, and mental health outcomes across different patient characteristics, which can inform care improvements for patients.[19]

Data Standardization

Patients with complex conditions, such as new moms managing postpartum health risks or people with sickle cell disease, often receive care across multiple health systems. As a result, their health information is recorded in different health system EHRs. Health systems may use different proprietary standards for clinical data (e.g., symptoms, diagnoses, medications, or results), meaning the same information may be represented differently in each system. When EHR data are not standardized across systems, they can be difficult to collect, link, and analyze. Consistent use of clinical definitions across EHRs enables PCOR and CER researchers to efficiently create large, multi-site datasets needed to generate generalizable insights and validly compare treatment effects across different patient populations.

Clinical data standardization is supported by the USCDI, a set of standards that define what information is collected and how it is structured and formatted, and other coding systems such as Logical Observation Identifiers Names and Codes (LOINC) for laboratory data.[20] However, these standards and coding systems are inconsistently adopted and implemented across EHRs due to a combination of technical, financial, regulatory, and workflow-related factors.[7,21,22]

OS-PCORTF projects are developing data elements to standardize information collected on maternal health outcomes and sickle cell disease research, and separately have created resources to help laboratories accurately and consistently apply data standards to laboratory data.

Improving outcomes for national health priorities, including maternal health and sickle cell disease, requires large amounts of data from disparate sources to understand the impact of interventions on patient outcomes.[23] Standardized data elements are necessary for researchers to efficiently aggregate EHR data from different health systems; however, there is variability in the availability of standardized data elements for these conditions.[24,25] For example, postpartum

hemorrhage, depression and anxiety, and other labor and delivery outcomes are inconsistently defined and reported across settings.

A series of Office of the National Coordinator for Health Information Technology (ONC) projects are reducing this variability to enable higher-quality evidence generation for these conditions. USCDI is the core set of health data elements required for nationwide exchange—a shared language across health IT systems. It includes data elements such as clinical notes, labs, allergies, and intolerances, laboratory test results, and medications. USCDI evolves every year based on public input, ensuring that the standard keeps pace with real-world needs. USCDI Plus (**USCDI+**) builds on the core data elements defined in the **USCDI** by identifying and establishing domain- or program-specific extensions to meet use-case needs. These USCDI+ extensions are developed through a collaborative process with federal and industry partners to ensure they are harmonized with existing standards and taxonomies, enabling more comprehensive interoperable data exchange for priority health and care activities.

Two OS-PCORTF projects are developing a USCDI+ data element list for sickle cell disease and **maternal health** data element set. Both USCDI+ sickle cell disease and the maternal health datasets provide guidance to health systems about which data standards to use for exchanging electronic health information between health systems.

Key Impact | Standardizing Postpartum Data to Reduce Maternal Disease

The postpartum mortality rate in the U.S. is increasing—and nearly two out of every three maternal deaths occur during the postpartum period.[26] The USCDI+ maternal health dataset, which contains 145 maternal health data elements including 24 new data elements related to care delivered in the postpartum period, will support higher-quality EHR data for exploring PCOR and CER questions related to maternal health care during and after birth. Building on this work, a health system will pilot test a postpartum transitions of care FHIR implementation guide that uses these data elements to improve gaps in postpartum care.

Laboratory data, such as hemoglobin A1c levels and lipid panels, are essential for diagnosing and monitoring many chronic health conditions, like diabetes and cardiovascular disease. Including laboratory test results in research datasets allows researchers to objectively assess disease severity and track treatment effectiveness over time.[27] Without clear guidance, different laboratories sometimes assign different LOINC codes to the same type of laboratory tests and results, impacting data quality and interoperability. For example, different laboratories may code tests used to diagnose and monitor diabetes differently, which can lead to incomplete or misleading datasets for studying diabetes prevalence or treatment outcomes.

A **U.S. Food and Drug Administration (FDA) project** improved the quality of laboratory data by developing six new LOINC code mapping guides. These LOINC mapping guides provide guidance to laboratories on how to assign the correct LOINC codes to laboratory tests and their results. The LOINC guides help ensure that laboratory information can be reliably stored, shared, and analyzed across different hospitals and health systems to study various conditions.

Key Impact | Standardizing Laboratory Data for Reliable Real-World Evidence

Standardized laboratory data is particularly valuable during public health emergencies, as researchers and policymakers rely on interoperable data from multiple health systems to monitor nationwide trends and guide response efforts. To improve the use of real-world data to inform regulatory decisions, the FDA-led team implemented the new **LOINC mapping specifications** to assess their effectiveness in harmonizing laboratory data across settings.[28] These mapping specifications helped eliminate guesswork when assigning LOINC codes and reduced LOINC variation within systems.

Creating Comprehensive Datasets

The development of high-quality, comprehensive datasets that integrate information from multiple health systems, sectors, and clinical registries is essential for understanding the underlying causes of disease and effective treatment options, particularly for addressing national public health challenges and emerging infectious threats. From a patient's perspective, comprehensive datasets that capture their health journey over time enable more informed, responsive, and personalized care that reflect the full scope of their health experiences.

Common data elements (CDEs) ensure uniform meaning and representation of health information across sources. Common data models (CDMs) provide a consistent framework for organizing and storing these elements. Together, they enable data harmonization—the process of aligning and integrating data from different systems—allowing researchers to aggregate and link data.

OS-PCORTF projects are developing data harmonization platforms and tools that enable researchers to create comprehensive, integrated datasets for more effective analysis.

Variability in how opioid-related data are collected in the EHR can limit efficient and effective analysis, slowing decision-makers' response to the opioid epidemic. To address this challenge, one **NIH/National Institute on Drug Abuse (NIDA) project** developed a data dictionary to improve the quality of opioid-related CDEs (e.g., for treatment history and medications) captured in emergency department EHRs. Health systems using the data dictionary improved the consistency of data reported to the nation's largest emergency department clinical registry, the Clinical Emergency Data Registry, by up to 90%.[29] A second **NIH/NIDA project** established a new addiction medicine practice-based research network, AMNet, using data from an existing mental health data registry. The project developed CDEs to electronically capture patient characteristics, medications for opioid use disorder (OUD), recovery services, patient-reported outcomes, and clinical quality measures, improving the quality of EHR data submitted by physician practices to the registry.

Registries typically focus on a single condition or treatment, which can limit insights for patients receiving multiple treatments or who have co-occurring conditions. To more comprehensively study how different medical devices and treatments affect women's health, a collaborative project between **FDA, NIH/National Library of Medicine, and ONC** created a network of three medical device registries. The project defined a minimum set of CDEs and a FHIR implementation guide to enable data from each registry to be combined and analyzed together, expanding the range and complexity of PCOR analyses beyond what a single registry could support.

Patients and clinicians managing complex conditions or new diseases with limited treatment options may rely on cutting-edge research to understand how to use existing drugs in novel ways to find relief. However, using EHR data to study new uses for existing drugs can be difficult without a structured data platform to collect and harmonize data for analysis. Additionally, patient-generated health data are critical for understanding disease outcomes important to patients, so it is essential to include these data in data analysis platforms. An **FDA and NIH/National Center for Advancing Translational Sciences-led project** enhanced their existing data platform, CURE ID, to allow for the automated extraction of de-identified patient-level data from EHRs to support the use of "off-label" drugs to treat an emergent infectious disease. It also developed a patient case report form where patients with any infectious disease or sequelae of infection (e.g., Long COVID), can submit information about their condition to CURE ID. The project standardized and harmonized relevant EHR and patient-generated health data into a widely used CDM, the Observational Medical Outcomes Partnership CDM. CURE ID now includes over 115,000 new treatment cases collected from health systems and more than 600 cases submitted by patients.

Key Impact | Leveraging EHR Data for Critical Care Research

The **EHR and clinical registry data extraction infrastructure** established for **CURE ID** is being leveraged by a public-private partnership, REDISCOVER-ICU. The aim of REDISCOVER-ICU is to establish a disease-agnostic, real-world data repository to support research on drug repurposing in critical care and to curate large, high-quality datasets to support observational research on diseases and conditions with high unmet clinical need.[30]

Access to complete patient health information is critical for research and public health interventions that keep communities safe and healthy. However, health systems do not always have the ability to easily, timely, or consistently share clinical data with research organizations or public health agencies, such as national research networks or state health departments, which may result in delay or underreporting of key patient-centered outcomes. Limited access to these critical electronic data can slow surveillance and research efforts and hinder the use of real-world data to inform public health responses. To help address this, a **CDC-led project** developed a FHIR-based application (app) and multiple implementation guides to enable automated electronic data exchange (e.g., **Reference Architecture**, **Health Care Surveys**, **Central Cancer Registry Reporting**, **Research Data Exchange**). The app automatically finds pre-specified data within the EHR and other systems, aggregates the data, and securely sends it to public health agencies or research organizations who are authorized to receive it. In doing so, the app improves the timeliness, availability, and completeness of clinical data for public health surveillance and research.[31, 32]

Coordinating care for individuals with multiple chronic conditions can be difficult because these individuals see many doctors, meaning their health data are dispersed across systems. A series of Agency for Healthcare Research and Quality (AHRQ) and NIH/National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) projects developed FHIR-based apps to aggregate EHR data from different care settings. The first iteration of the **AHRQ and NIH/NIDDK project** developed an app for clinicians that supports care coordination for patients with chronic kidney disease, diabetes, heart disease, chronic pain, or OUD. This app also makes it easy to share data on the care and outcomes of individuals with complex health needs with researchers. The second **AHRQ and NIH/NIDDK project** created an app that improved patients' access to their EHR data, allowing them to see their health data in one place, track goals, and share information with their care teams.

The lack of standardized, linked maternal-infant clinical data has hindered researchers' ability to assess how clinical history, risk factors, and additional exposures affect pregnancy outcomes for women with OUD. A series of CDC projects built a multi-site surveillance network, the MATernaL and Infant NetworK (**MAT-LINK 1.0** and **MAT-LINK 2.0**), to use real-world data to guide health care decisions, improve treatment during pregnancy, and support healthier outcomes for mothers and their children. The network captures EHR treatment and outcomes data (e.g., medications, polysubstance use, comorbidities, and pregnancy outcomes) for pregnant women with OUD linked to outcomes data about their children (e.g., early childhood health and development).

Key Impact | Improving Opioid Treatment Options for Pregnant Moms

The **MAT-LINK dataset** consists of almost 6,000 pregnant woman-infant pairs from seven clinical sites across the U.S. The high-quality, standardized data from the MAT-LINK surveillance system is continually being used by external researchers to answer PCOR questions. For example, researchers are using these data to examine patterns of medication treatment for OUD during pregnancy,[33] Naloxone prescribing and administration in response to overdose events,[34] prevalence of post-traumatic stress disorder,[35] and sensitivity and specificity of International Classification of Diseases, Tenth Revision (ICD-10) codes for drug overdose events among pregnant women with OUD.[36]

Data Governance

Responsible use of EHR data for PCOR and CER requires clear governance frameworks that facilitate EHR data liquidity while ensuring trust through appropriate use rules and patient privacy protections.

In addition to improving the quality, interoperability, and use of linked EHR data for research, OS-PCORTF projects strengthen the governance structures that guide how these data are shared and used for research.

Data governance frameworks are a key tool to transform fragmented real-world data into a coordinated, trusted, and reusable research asset. These frameworks often complement federal and state privacy and security laws, including for the secondary use of EHR data for research and population health.[37,38] Governance frameworks also advance patient agency by empowering patients to take control over whether their health data can be used for research and who can access their health data. Ensuring all data sharing participants are playing by the same data sharing rules supports the use of large volumes of patient-level data for research.

Public health agencies' and research organizations' access to needed data from health systems can be slow and inefficient. A **CDC-led project** developed the Making Electronic Data More Available for Research and Public Health (MedMorph) "reference architecture," a framework for using FHIR to access electronic data from EHRs and other data sources. The reference architecture describes, at a high level, a consistent and reproducible approach for health systems to automate data exchange to facilitate reporting and data collection, thus providing a consistent foundation upon which use case-specific implementation guides can be developed.

Key Impact | Reducing Health Systems' Public Health and Research Reporting Burden

The CDC team piloted the **MedMorph Reference Architecture** using hepatitis C as a test case. Compared to traditional and manual reporting methods that can take days, MedMorph automatically sent near real-time hepatitis C-related health data to a public health authority and research organization that included enough clinical detail to support more efficient public health investigations and research studies, ultimately improving disease management and epidemic prevention.[31] The CDC also developed an accompanying Substitutable Medical Applications, Reusable Technologies (SMART) on FHIR app and implementation guides that facilitate automated electronic data exchange for infectious disease, chronic disease, health care utilization, and research.

Privacy-preserving record linkage (PPRL) is one way to link patient records without sharing personal identifying information. Secure linkage approaches are important for protecting individuals' privacy while enabling meaningful research and analysis.

Information about medical and non-medical factors that affect childhood weight management can be recorded in settings outside of the doctor's office, such as schools, daycare, and other community settings. However, the flow of information between clinical and community settings has been limited by the lack of clear governance policies and data sharing agreements. To support the exchange of childhood obesity intervention data, the **CDC Childhood Obesity Data Initiative (CODI)** project developed a governance framework to implement PPRL between health systems and community organizations collecting non-medical data.

Key Impact | Building Trust to Link Data to Reduce Childhood Obesity

The stakeholder-driven governance framework, and standardized data use agreements, established trust among data users supporting secure, scalable patient-level data linkage while minimizing burden on data contributors.[39] Additionally, the CDC created a **PPRL implementation guide** to help health systems implement PPRL using standard data interfaces. The implementation guide was used by North Carolina to examine chronic disease outcomes for adults receiving community-based services.

Summary

An innovative, world-class U.S. research infrastructure requires a nationally integrated, standardized, interoperable, and patient-centered data ecosystem. The projects featured in this case study highlight the collective efforts of the OS-PCORTF portfolio to strengthen the real-world data infrastructure for conducting rigorous and impactful PCOR and CER. These projects expand the capacity of clinical registries and distributed health networks to collect, link, and analyze EHR data, informing better health care decision making and better health outcomes for Americans. Future national efforts to build a robust research data infrastructure should leverage these OS-PCORTF contributions.

For more information about the OS-PCORTF projects described in this report, please reach out to **OSPCORTF@hhs.gov**

References

[1] Make America Healthy Again Commission. Make Our Children Healthy Again: Strategy Report. 2025. Available from https://www.whitehouse.gov/wp-content/uploads/2025/09/The-MAHA-Strategy-WH.pdf.

[2] Conway PH, Clancy C. Comparative-effectiveness research--implications of the Federal Coordinating Council's report. *N Engl J Med.* 2009;361(4):328-330. doi:10.1056/NEJMp0905631

[3] Patient-Centered Outcomes Research Institute. What is CER and Why Does it Matter? July 25, 2025. Available from https://www.pcori.org/blog/2025/what-cer-and-why-does-it-matter

[4] Office of the National Coordinator for Health Information Technology. 'National Trends in Hospital and Physician Adoption of Electronic Health Records,' Health IT Quick-Stat #61.

[5] Tang AS, Woldemariam SR, Miramontes S, Norgeot B, Oskotsky TT, Sirota M. Harnessing EHR data for health research. *Nat Med*. 2024;30(7):1847-1855. doi:10.1038/s41591-024-03074-8

[6] Sarwar T, Seifollahi S, Chan J, Zhang X, Aksakalli V, Hudson I, Verspoor K, Cavedon L. The secondary use of electronic health records for data mining: data characteristics and challenges. *ACM Computing Surveys (CSUR).* 2022 Jan 18;55(2):1-40. doi:10.1145/3490234

[7] El-Yafouri R, Klieb L. A scoping review of electronic health records interoperability levels, expectations, approaches, and problems. *Health Informatics J*. 2025;31(4):14604582251385986. doi:10.1177/14604582251385986

[8] Li E, Clarke J, Ashrafian H, Darzi A, Neves AL. The impact of electronic health record interoperability on safety and quality of care in high-income countries: Systematic review. *J Med Internet Res*. 2022;24(9):e38144. doi:10.2196/38144

[9] Office of the National Coordinator for Health Information Technology. *21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program.* Fed Regist. 2020;85(85):25642-25961

[10] Office of the National Coordinator for Health Information Technology. Cures Act Final Rule United States Core Data for Interoperability (USCDI). March 2020. Accessed May 21, 2026. Available from: https://www.healthit.gov/sites/default/files/page2/2020-03/USCDI.pdf

[11] Centers for Medicare and Medicaid Services. Interoperability Framework. July 31, 2025. Accessed May 21, 2026. Available from: https://www.cms.gov/health-technology-ecosystem/interoperability-framework

[12] Sequoia Project. Trusted Exchange Framework and Common Agreement (TEFCA) Washington (DC): Recognized Coordinating Entity (RCE). Accessed May 21, 2026. Available from: https://rce.sequoiaproject.org/tefca/

[13] Office of the National Coordinator for Health Information Technology. HHS Aligns Health Technology Leadership to Deliver Data Liquidity, Affordability, and an AI-Enabled Health Care System for Americans. March 31, 2026. Available from: https://healthit.gov/news/hhs-aligns-health-technology-leadership-to-deliver-data-liquidity-affordability-and-an-ai-enabled-health-care-system-for-americans/

[14] Office of the National Coordinator for Health Information Technology. Interoperable Exchange of Patient Health Information Among U.S. Hospitals: 2023. May 2024. Accessed May 21, 2026. Available from: https://www.healthit.gov/wp-content/uploads/2024/05/Interoperable-Exchange-of-Patient-Health-Information-Among-U.S.-Hospitals-2023.pdf

[15] Gabriella Miller Kids First Data Resource Center. About Kids First Data Resource Center. Accessed April 7, 2026. Available from: https://kidsfirstdrc.org/about/

[16] Human Resources and Services Administration. About the Health Center Program. Accessed May 21, 2026. Available from: https://bphc.hrsa.gov/about-health-center-program

[17] Gourevitch RA, Hatfield LA. Changes in prenatal care and birth outcomes after federally qualified health center expansion. *Health Serv Res*. 2023;58(2):489-497. doi:10.1111/1475-6773.14099

[18] Williams SN, Ukaigwe J, Ward BW, Okeyode T, Shimizu IM. Sampling procedures for the collection of electronic health record data from federally qualified health centers, 2021-2022 national ambulatory medical care survey. *Vital Health Stat 1*. 2023;(203):1-16.

[19] Guluma L, Ward BW, Williams SN, Zhang C, Golden C. Data Resources for Conducting Patient-Centered Outcomes Research at Federally Qualified Health Centers: The National Ambulatory Medical Care Survey. *Med Care*. 2026;64(3):128-134. doi:10.1097/MLR.0000000000002274

[20] Office of the National Coordinator for Health Information Technology. Interoperability Standards Platform. United States Core Data for Interoperability (USCDI). Accessed May 28, 2026. Available from: https://isp.healthit.gov/united-states-core-data-interoperability-uscdi

[21] Park HA. Why terminology standards matter for data-driven artificial intelligence in healthcare. *Ann Lab Med*. 2024;44(6):467-471. doi:10.3343/alm.2024.0105

[22] Marfoglia A, Arcobelli VA, Moscato S, La Mattina AA, Mellone S, Carbonaro A. Challenges of health data standard adoption and usage: a systematic review. *J Biomed Inform*. 2026;178. doi:10.1016/j.jbi.2026.105022

[23] Nijagal MA, Wissig S, Stowell C, et al. Standardized outcome measures for pregnancy and childbirth, an ICHOM proposal. *BMC Health Serv Res*. 2018;18(1):953. doi:10.1186/s12913-018-3732-3

[24] *Enhancing Data Infrastructure to Improve Women's Health Outcomes*. Washington (DC): Office of the Assistant Secretary for Planning and Evaluation (ASPE); October 2022. Available from: https://www.ncbi.nlm.nih.gov/books/NBK605937/

References

[25] Smeltzer MP, Reeves SL, Cooper WO, et al. Common data model for sickle cell disease surveillance: considerations and implications. *JAMIA Open*. 2023;6(2):ooad036. doi:10.1093/jamiaopen/ooad036

[26] Munira Gunja et al., Insights into the U.S. maternal mortality crisis: An international comparison. Commonwealth Fund; June 2024. https://doi.org/10.26099/cthn-st75

[27] Gounden V, Banerjee M, Amundsen EK, et al. Linking laboratory testing to clinical outcomes: Bridging the gap through outcome-based studies in laboratory medicine. *Clin Chem*. 2023;69(11):1317-1321. doi:10.1093/clinchem/hvad132

[28] Cholan RA, Pappas G, Rehwoldt G, et al. Encoding laboratory testing data: Case studies of the national implementation of HHS requirements and related standards in five laboratories. *J Am Med Inform Assoc.* 2022;29(8):1372-1380. doi:10.1093/jamia/ocac072

[29] Hawk K, Malicki C, Kinsman J, D'Onofrio G, Taylor A, et al. Project CODE-PRO Capturing Opioid Use Disorder Electronically and Patient Reported Outcomes. January 2021. Access May 7, 2026. Available from: https://aspe.hhs.gov/sites/default/files/private/pdf/259016/ctn-0081-final-report.pdf

[30] The Society of Critical Care Medicine. REDISCOVER-ICU. Accessed April 29, 2026. Available from: https://www.sccm.org/research/discoveryresearch-network/discovery-research-collaboratives/rediscover-icu

[31] Michaels M, Botts NE, Hassell S, et al. Initial real-world pilot of the MedMorph reference architecture: Hepatitis C surveillance and research. *Appl Clin Inform*. 2025;16(2):234-244. doi:10.1055/a-2441-6100

[32] Michaels M, Syed S, Lober WB. Blueprint for aligned data exchange for research and public health. *J Am Med Inform Assoc*. 2021;28(12):2702-2706. doi:10.1093/jamia/ocab210

[33] Tran EL, Dorsey AN, Miele K, et al. Patterns of medication for opioid use disorder during pregnancy, 7 clinical sites, MATernaL and Infant clinical NetworK (MAT-LINK), 2014-2021. *J Addict Med*. 2025;19(2):208-215. doi:10.1097/ADM.0000000000001426

[34] Schrote K, Board A, Thomas SA, et al. Naloxone prescribing and naloxone administration in response to overdose events among women with opioid use disorder during pregnancy and postpartum period - MAT-LINK, Seven clinical sites, 2014-2021. *J Addict Med*. Published online January 26, 2026. doi:10.1097/ADM.0000000000001655

[35] Peck KR, Chen MH, Lee B, et al. Estimated prevalence of current posttraumatic stress disorder among pregnant women with opioid use disorder-MATernaL and Infant Clinical NetworK (MAT-LINK), 2014-2021. *J Addict Med*. Published online February 23, 2026. doi:10.1097/ADM.0000000000001667

[36] Board A, Vivolo-Kantor A, Kim SY, et al. Using ICD codes alone may misclassify overdoses among perinatal people. *Am J Prev Med*. 2025;68(3):563-570. doi:10.1016/j.amepre.2024.12.001

[37] Office of the National Coordinator for Health Information Technology. Legal and Ethical Architecture for PCOR Data. September 28, 2017. Accessed May 21, 2026. Available from: https://www.healthit.gov/sites/default/files/page/2018-06/PCOR%20Architecture%20%28MERGE%29%20updated%20Appendix%20B.pdf

[38] National Conference of State Legislatures. State Laws Related to Digital Privacy. Updated October 10, 2025. Accessed May 21, 2026. Available from: https://www.ncsl.org/technology-and-communication/state-laws-related-to-digital-privacy

[39] Kraus EM, Scott KA, Zucker R, et al. A governance framework to integrate longitudinal clinical and community data in a distributed data network: The childhood obesity data initiative*. J Public Health Manag Pract.* 2022;28(2):E421-E429. doi:10.1097/PHH.0000000000001408