OSPCORTF
OFFICE OF THE SECRETARY PATIENT CENTERED OUTCOMES RESEARCH TRUST FUND

BUILDING DATA CAPACITY FOR PATIENT-CENTERED OUTCOMES RESEARCH

Portfolio Highlights (2016 – 2019)

Impact, Opportunities, and Case Studies

Executive Summary

ASPE
ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
OFFICE OF HEALTH POLICY

Building Data Capacity for Patient-Centered Outcomes Research

Portfolio Highlights (2016 – 2019)
Impact, Opportunities, and Case Studies

Executive Summary

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Executive Summary

Since FY 2010, HHS under the OS-PCORTF has funded approximately 70 awards representing diverse and large-scale data infrastructure projects. The purpose of this report is to demonstrate the impact of the OS PCORFT portfolio. What are the products, tools and lessons learned for future work? ASPE contracted with NORC at the University of Chicago (NORC) to undertake a three pronged approach. First, they assessed a subset (43) of awards based on the OS PCORTF strategic framework. Secondly, they assessed the portfolio relative to agencies' specific data strategies to identify additional opportunities to enhance data infrastructure for patient centered outcome research. Third, they conducted a deeper dive into twelve projects that advanced priorities in data infrastructure, including standardization, interoperability and linkages. NORC also convened a Technical Expert Panel (TEP) of research and industry stakeholders on strategic direction. Together, these approaches and the TEP commentary offer suggestions for future areas of focus to build data capacity.

Background

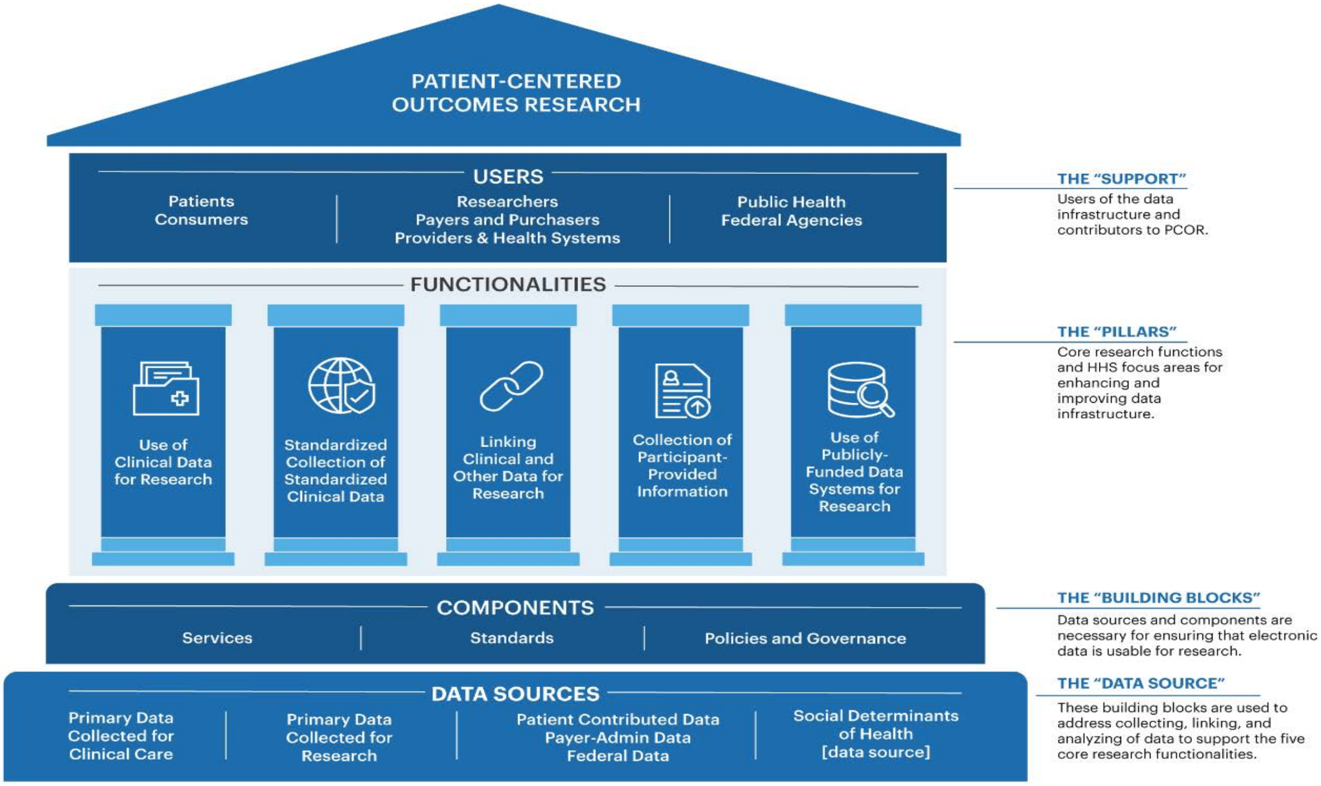
A central goal of building data capacity under the OS-PCORTF is to support HHS research programs that generate scientific evidence that informs decisions about patient-centered care delivery. HHS agencies routinely collect, link, and analyze data to assess federal programs and the patient populations these programs serve. These data are foundational to research that expands knowledge about the outcomes and effectiveness of health care treatments and interventions. Major HHS initiatives like using "real-world evidence" to bring new treatments to patients as part of the 21st Century Cures Act (the "Cures Act"), the historic National Institutes of Health (NIH) *All of Us* Research Program that will gather health information from 1 million or more Americans to accelerate research and improve health, and the many efforts to address the opioid crisis in the United States require high quality data and the tools to collect, analyze, and generate research and health insights from it. As a consumer, producer, and regulator of key national health data, HHS is uniquely positioned to coordinate its programs to build national data capacity in support of the mission, statutory authorities, and annual priorities of each HHS agency and the Department as a whole.

Strategic Framework

Given the OS-PCORTF's statutory charge to "coordinate federal programs to build data capacity … including the development and use of clinical registries and health outcomes research networks," the portfolio focuses on the needs of research networks that use data to conduct health outcomes studies that address patient-centered questions or concerns. In partnership with the OS-PCORTF Leadership Council,[1] ASPE developed the *HHS Strategic Roadmap for Building Data Capacity for Clinical Comparative Effectiveness Research* to guide the portfolio work (see Exhibit 1).

The framework contains "building blocks," or the data sources and components, ensure that electronic data is usable for patient-centered research.[2] The "pillars" in the middle of this structure represent the core research "functionalities" that are the key focus areas for the OS-PCORTF portfolio to enable more robust data for end-users. Eighteen milestones have been specified across the five functionalities to serve as benchmarks of progress toward achieving the functionalities (see Appendix A). Together, the functionalities and milestones provide a method for assessing the impacts of the portfolio and identifying areas where additional work can be done.

Exhibit 1. OS-PCORTF Strategic Framework



Chapter 1-Portfolio Assessment

The portfolio assessment consisted of three distinct analyses: 1) an assessment of the extent to which these awards are advancing the Strategic Framework functionalities; 2) a gap analysis to determine how well the portfolio addresses the gap areas identified by the 2017 Evaluation; and 3) a review of the portfolio's contribution to emerging HHS policy priorities. See Appendix B for the full list of awards included in the analysis and Appendix C for evaluation gap criteria.

Extent to Which the Portfolio Advances the Strategic Framework

Almost 75 percent of the awards focus on **optimizing clinical data** for research applications. This includes developing tools and services that support researchers in analyzing clinical data from multiple sources (e.g., Electronic Health Records, claims, registries, and patient portals), as well as tools and services that improve the quality of data as they are collected, so they are better suited for research. For example, a FY 19 CDC award is making clinical data more accessible for research and public health surveillance by developing an application that enables real-time data exchange between EHRs and public health systems.

Just over 50 percent of the awards are working to **enhance the use of publically funded datasets for research** by increasing researcher access to the data, linking federal datasets to other useful data sources, and facilitating research analysis of the data. For example, AHRQ and ASPR are collaborating on a FY 18 project to build a platform brings together an expanded Healthcare Cost and Utilization Project (HCUP) dataset with other data sources to support research questions about the effectiveness of different disaster response and recovery interventions.

Roughly 50 percent of the awards focused on **standardizing data collection**. This includes defining common data elements so that data can be collected, linked, and analyzed across multiple data sources. For example, AHRQ and the NIH's National Institute of Diabetes and Digestive and Kidney Diseases are developing an electronic care plan to collect data from across the continuum of care using new and expanded data elements to capture information on patients with multiple chronic conditions for use in pragmatic trials.

Nearly 50 percent of awards are developing tools to **collect participant provided information to support participation in research**. The Agency for Healthcare Research and Quality (AHRQ) and The Office of the National Coordinator for Health (ONC) are collaborating on a project to standardize the integration of patient reported outcomes data in EHRs and other health IT solutions. This would allow for patient report outcome assessments to be conducted and easily shared regardless of what EHR or health IT solution is being used. It would also allow for consistency in interpretation and would clarify the meaning of results for patient-provider communication and shared decision-making. This effort will also support the use of APIs (application programming interface).

Twenty-five percent of awards focused on **linking data**, including some awards that are enhancing federal datasets that are highly valued by health care researchers. These datasets are being linked together to support expanded research inquiries. For example, a CDC project is using a linked dataset that combines National Hospital Care Survey (NHCS) data and National Death Index (NDI) data, and developing new algorithms that can help researchers more easily identify opioid-related deaths among this data. Being able to separate opioid-related deaths means researchers can conduct opioid-targeted research more efficiently.

Extent to Which the Portfolio Addresses Gaps Identified by the 2017 Evaluation

RTI conducted an evaluation of the portfolio in 2017 and NORC conducted an assessment of how the portfolio had addressed the gaps identified. See appendix C for the gaps identified and the criteria used to address them.

The most frequently addressed gap area was **disseminating research findings**. Nearly every award described plans for publicly dissemination, with some projects already disseminating OS-PCORTF products to end-users, such as posting software code to open source platforms like GitHub.

The portfolio made progress closing gaps around **standards and improving data quality**. For example, multiple projects are improving data quality and enhancing interoperability by developing, piloting, and refining implementation guides through organizations like Health Level Seven (HL7) and standards efforts such as Fast Healthcare Interoperability Resources (FHIR®). Data standardization, improved data access, and ease of data exchange is critical in rendering health information useful for clinical and research purposes.

Extent to Which the Portfolio Has Evolved to Meet the Emerging Health Policy Landscape

Early portfolio work focused on data linkages, increased access to federal datasets, and improvements in clinical registries and research networks. For example, several awards are working to enhance the utility of federal datasets such as the NDI and Sentinel. Several projects are supporting the interoperability objectives of the Cures Act to enable the secure exchange of electronic data without special effort by pilot testing application programming interfaces (APIs).

Later work has expanded to advance next-generation interoperability, improve patient access to health information, and accelerate growth in advanced data science techniques. For example, one FY 2019 award is creating research-quality synthetic datasets to complement the use of real-world data and allow for more rigorous analysis. This shift in focus correlated with shifts in the policy landscape, which prioritizes patient engagement in research and clinical care, enhanced interoperability, and data sharing.

Technical Expert Panel Feedback

The TEP provided feedback in three areas: 1) potential areas of refinement to the Strategic Framework; 2) PCOR data infrastructure needs that should be prioritized in future portfolio activities and 3) metrics to assess portfolio impact going forward.

How Can the Strategic Framework Be Refined?

- Integrating external factors that can influence the data sources, data infrastructure, and types of patient-centered research inquiries that are carried out, such as financial and policy drivers that influence provider documentation and the social determinants that impact health outcomes.
- Identifying and incorporating cross-cutting barriers that can impede progress in patient-centered research.
- Emphasizing the role of data provenance as a key component that influences data usability for research.
- Establishing and consulting with working groups for each of the five functionalities who can advise on relevant federal initiatives that could be leveraged by the portfolio, metrics for assessing progress of the functionality, and the evolving needs related to that functionality.

What Priorities Should ASPE Consider for Future Work?

- Addressing the non-technical barriers that impede the use and sharing of data for research including data governance and privacy and security protections.
- Providing targeted support and guidance to projects teams with products that are ready for translation of their work for broader uptake.
- Engaging end-users during the planning phases of project awards to identify areas of greatest need, support translation of products, and inform sustainability efforts.

What Metrics are Needed to Understand the Impact of the Portfolio on Building Data Capacity for PCOR?

- Portfolio-wide metrics including metrics that track and quantify artifacts that are used by other project awards and metrics derived from a more prescriptive strategic roadmap that can assess progress along the roadmap;
- Award-specific metrics to assess whether each individual award achieved its articulated objectives;
- Dissemination and translation metrics that track the number and type of dissemination products, use of website analytics (e.g., measuring website traffic and counting the number of downloads of posted material), and tracking the ways in which other research initiatives leverage award outputs.

Chapter 2-Synergies with Agency Specific Data Strategies

Patient-centered outcomes research prioritizes the patient in the design, conduct, and reporting of research, with the goal of generating new scientific evidence that informs decision-making and patient care and improves health outcomes. Chapter 2 is intended to foster discussion about areas in which building data capacity for patient centered outcome research is of cross-agency interest. The chapter does so by examining the HHS Data Strategy, OS-PCORTF Strategic Framework, and other selected agencies' data initiatives to identify areas that are pertinent to the goals of patient-centered outcomes research.

The OS-PCORTF functionalities and its portfolio are aligned with the HHS Data Strategy. Further, the awards have created products that support agencies' data strategies.

The awards have created tools, guides, frameworks, and other solutions that contribute to the data strategies of multiple agencies. As such, resources from these awards could be disseminated to and used by HHS agencies to accelerate the pace of patient-centered outcomes research. Lessons learned from the awards could be applied by HHS agencies pursuing their own projects and serve as building blocks for new or related work within an agency.

The HHS agency frameworks and data strategies indicate a cross-agency recognition of the importance of interoperability and data-sharing to support patient-centered research and knowledge generation.

The agency-specific data strategies lay out priorities for each agency's upcoming activities with regard to research and data infrastructure projects. Across the strategies, there is agreement that robust research relies on equally robust data infrastructure in which: 1) health information can be shared among multiple stakeholders (e.g., patients, providers, hospital systems, federal agencies); 2) the health information being shared consists of high quality data; and 3) researchers have access to useful tools to gather and analyze this data to generate new knowledge. Finally, it is a cross-agency priority that the health information being shared and analyzed for research must be protected.

A common theme across HHS data frameworks is the importance for agencies to learn from and collaborate with one another in pursuing their research and data priorities.

Most, if not all, awards involve cross-agency collaboration either through joint agency funding or through the use of TEPs or steering committees. These partnerships demonstrate how multi-agency coordination can positively impact efforts to build data infrastructure and support the researchers conducting PCOR. Such collaborations would be beneficial to continue in the future, and these projects may offer best practices for doing so.

Technical Expert Panel Feedback

The TEP offered their thoughts as the portfolio continues to seek opportunities to lead, collaborate, and support the development of data infrastructure and other initiatives that support patient-centric research.

What Role Can the Portfolio Play in Continued PCOR Development?

- The portfolio has played a consistent role in bringing agencies together in partnerships and knowledge-sharing. In addition to leading by example with the OS-PCORTF portfolio, there are several other avenues in which its leadership can advance the field: such as dissemination, convening, and formation of a brain trust to further awareness of and participation in PCOR among diverse research stakeholders.
- Having already built numerous relationships with agencies and researchers via the OS-PCORTF awards, the portfolio leaders are well positioned to continue its coordination efforts of patient-centric efforts across the department.
- The TEP suggested that in areas that are outside of the portfolio’s purview and/or already being addressed by other agencies, the portfolio could contribute to these efforts in a supportive way (e.g., contributing to the development of a federal catalog of data assets and other aggregate resources).

Chapter 3-Case Studies

The case studies describe activities and products for 12 OS-PCORTF awards that have enhanced the data infrastructure for patient-centered research, contributing to the current and emerging applications of data science in the health field. The cases studies were organized into four themes related to their contributions: 1) data interoperability and novel approaches to enhancing researchers’ access to participant-reported and patient-donated data; 2) data standardization; 3) enhancements to the National Death Index (NDI); and 4) data linkages. The case studies underscore the importance of focusing product development toward addressing end-user need and identifying strategies to support the use of those products by the intended end-user community.

Technical Expert Panel Feedback

In their discussion about the direction of future work, the TEP offered input on strategies to ensure that the work of portfolio has enduring value and maximizes the opportunities and mechanisms to support engagement between awardees and end-users. Progress in these areas is a key component of promoting the translation of portfolio products, outputs, and lessons learned to real-world implementations with the goal of achieving long-term sustainability.

What activities can be pursued to ensure that the work has enduring value?

The TEP discussed ways ASPE could develop a framework or guide for future OS-PCORTF awardees to help them integrate sustainability planning into their projects. This framework could be integrated into the application process whereby the applicant articulates their plan for sustainability with a particular emphasis on the value of the work to patients, the end-user, and to the organization that collects or owns the data.

Recognizing the importance of translation, the TEP provided ideas for increasing the spread and uptake of portfolio products. One suggestion for improving translation is to identify a Community of Practice (CoP) a priori for the award and the resulting assets. A CoP can help steer decision-making around the product dissemination, and identify challenges and barriers to address future product development. A CoP can also facilitate engagement and new partnerships among stakeholders who have not worked together previously, but who share a common data or infrastructure need.

Because many of the awards in the portfolio are highly technical in nature, product uptake might improve if the general researcher community had a better understanding the products and how they can be applied in different research contexts. OS-PCORTF awardees could be encouraged to develop resources such as a demonstration module that could quickly help potential users determine whether the product is a good fit for their needs.

The TEP suggested that the OS-PCORTF products be made more readily available. This includes not just final tools, reports, and datasets, but interim products, such a methodologies and linkage algorithms. The TEP suggested dissemination of links and a public facing website that ensures products can be searched and found via the internet.

What non-traditional opportunities or platforms for products, outputs, or learnings could be leveraged to support engagement between researchers and end-users?

- Professional associations can serve as the vehicle for engaging providers during the early stages of a project to assess interest and secure buy-in for the resulting products.
- The TEP suggested that the OS-PCORTF portfolio look for opportunities to promote marketing or business development during pre- and post-award. First, as part of idea generation and concept planning, there should be some intelligence gathering to gauge the need and interest in the work prior to pursuing an award. Second, to raise awareness among end-users, products should be promoted and marketed upon completion. Building this information gathering into idea generation and dissemination may improve translation of products that are designed to fit a stated need.
- Code-a-thons, datathons, and challenge competitions are a widely-used industry tool for quickly testing and developing innovative solutions to technical challenges. ASPE should continue to encourage the use of these low-cost collaborative learning activities to test and disseminate OS-PCORTF products that allows for some real-world testing and offers opportunities for refinement.
- In coordination with its agency partners, ASPE could consider creating a dissemination platform or website that describes all of the products developed through the OS-PCORTF and content areas they address to help people identify products that are fit-for-purpose.

Conclusion

The five functionalities of the OS-PCORTF Strategic Framework have each been addressed by the 43 awards initiated between FY 2016 and FY 2019. These awards have also made headway in closing gaps identified by the prior 2017 Evaluation, particularly around the dissemination of products, as well as in implementing standards and improving data quality. While fewer awards have addressed enhancing data governance and balancing access with enhanced privacy and security, the products of these awards have made significant contributions in increasing data access.

Looking into the future, there are numerous opportunities for the portfolio to lead, coordinate, and support HHS activities. Broadening the agency’s dissemination of the OS-PCORTF products, as well as broadening awareness of PCOR itself among potential agency partners and other stakeholders, was a key theme during the TEP discussion. Facilitating departmental-level thinking about PCOR strategy, including among external stakeholders, and allowing that to inform the agency’s work was another key suggestion for leveraging existing relationships. There are areas where other agencies are natural leads and the portfolio could play an important supporting role, such as in contributing data and knowledge to help populate the multiple federal repositories being built to support stakeholders in identifying, accessing, and using data for patient-centered research. As HHS plans for the future, there are multiple opportunities to bolster the sustainability of the portfolio. Sustainability planning can be integrated into the award planning process to encourage more proactive identification of end-users who will utilize the products upon project completion.

Acknowledgements

The authors gratefully acknowledge contributions of the many federal agency partners who carried out the project activities of the OS-PCORTF portfolio which are described within this report.

Case Study Contributions

The content of the case studies presented in the third chapter of this report was informed by a webinar series which featured presentations of several individuals involved with OS-PCORTF project award activities. We acknowledge the important contributions of the following individuals who presented during the webinar series and reviewed drafts of the case studies:

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Technical Expert Panel

The authors sought to incorporate diverse perspectives of end-users of data infrastructure for patient-centered outcomes research and therefore convened a technical expert panel (TEP) of researcher and industry stakeholders. The TEP members were consulted throughout the development of this report over the course of two virtual and one in-person meeting and provided individual input as opposed to collective recommendations. The authors thank the following individuals for their insightful input:

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Appendix A. Strategic Framework Milestones by Functionality

Functionality	Milestones
Use of Clinical Data for Research	
	▪ Establish services and tools to support data access, querying, and use, including privacy-preserving analytics and queries.
	▪ Develop standards that support secure, electronic query of structured data across clinical research and delivery systems, including standards for open-source access.
	▪ Develop and test metadata standards that describe data quality.
	▪ Create a policy framework for privacy-preserving access and querying of clinical data by researchers conducting PCOR, and policies that govern the use of the services that support data access, querying, and use.
	▪ Develop a policy framework for ensuring clinical data used for research is of "research grade."
Standardized Collection of Standardized Clinical Data	
	▪ Support the development of a set of research CDEs in specific gap areas and support development of a governance structure for CDE harmonization
	▪ Support the development of repositories/portals for CDEs, standards for utilizing CDEs for research, and services to allow researchers to easily utilize standardized components.
	▪ Support research and/or crowd-sourced methods to determine which of the standardized collection components and services are most valuable.
	▪ Create policies to promote the adoption and use of valuable standardized collection components and services.
Linking Clinical and Other Data for Research	
	▪ Leverage existing standards and support the development and balloting of needed standards for patient data linkage.
	▪ Establish HHS policies that promote appropriate data-linking based on the framework noted in the milestone above.
	▪ Create a policy framework to facilitate patient data linkage in accordance with existing laws.
Collection of Participant-Provided Information	
	▪ Support the development of tools and services to facilitate the collection and exchange of PPI.
	▪ Support the development of a core set of standards for the collection and integration of prevalent use cases of PPI for PCOR, by leveraging existing standards and filling gaps.
	▪ Create policies and share best practices for collection and integration of prevalent use cases of PPI for PCOR.
Use of Enhanced Publicly Funded Data Systems for Research	
	▪ Support the enhancement of strategic publicly funded data systems (including CMS data) to facilitate their access and use, and ease retrieval of data for research purposes.
	▪ Support the further development of key federally initiated data systems for research.

Appendix B. Awards Included in the Impact Report

Agency	Award Title
Agency for Healthcare Research and Quality (AHRQ)	
	▪ Capstone for Outcomes Measures Harmonization Project
	▪ Enhancing Patient-Centered Outcomes Research (PCOR): Creating a National Small-Area Social Determinants of Health (SDOH) Data Platform
	▪ Harmonization of Clinical Data Element Definitions for Outcome Measures in Registries
Centers for Disease Control and Prevention (CDC)	
	▪ Augmenting the National Hospital Care Survey (NHCS) Data through Linkages with Administrative Records: A Project
	▪ Childhood Obesity Data Initiative: Integrated Data for Patient-Centered Outcomes Research Project (CODI)
	▪ Enhancing Identification of Opioid-Involved Health Outcomes Using Linked Hospital Care and Mortality
	▪ Identifying Co-Occurring Disorders among Opioid Users Using Linked Hospital Care and Mortality Data: Capstone to an Existing FY18 PCORTF Project
	▪ Making Electronic Health Record (EHR) Data More Available for Research and Public Health
	▪ Strengthening the Data Infrastructure for Outcomes Research on Mortality Associated with Opioid Poisonings
	▪ Surveillance Network: Maternal, Infant, and Child Health Outcomes Following Treatment of Opioid Use Disorder During Pregnancy
Centers for Medicare and Medicaid Services (CMS)	
	▪ Improving Beneficiary Access to their Health Information through an Enhanced Blue Button Service (Blue Button 2.0)
Food and Drug Administration (FDA)	
	▪ Bridging the PCOR Infrastructure and Technology Innovation through Coordinated Registry Networks (CRN) Community of Practice (COP)
	▪ SHIELD—Standardization of Lab Data to Enhance Patient-Centered Outcomes Research and Value-based Care
	▪ Source Data Capture from Electronic Health Records: Using Standardized Clinical Research Data (OneSource)
	▪ Standardization and Querying of Data Quality Metrics and Characteristics for Electronic Health Data
National Institutes of Health (NIH)	
	▪ Creation of LOINC Equivalence Classes
	▪ Emergency Medicine Opioid Data Infrastructure: Key Venue to Address Opioid Morbidity and Mortality
	▪ NIDA’s AMNET: An Addiction Medicine Network to Address the United States Opioid Crisis
	▪ Use of the ADAPTABLE Trial to Strengthen Methods to Collect and Integrate Patient Reported Information with Other Data Sets and Assess Its Validity

Agency	Award Title
Office of the National Coordinator for Health Information Technology (ONC)	
	▪ A Synthetic Health Data Generation Engine to Accelerate Patient-Centered Outcomes Research
	▪ Training Data for Machine Learning to Enhance Patient-Centered Outcomes Research (PCOR) Data Infrastructure
Cross-Agency Funded Awards	
	▪ Advancing the Collection and Use of Patient-Reported Outcomes through Health Information Technology [two awards dispersed: AHRQ (N=1, ONC (N=1)]
	▪ Assessing and Predicting Medical Needs in a Disaster [two awards dispersed: AHRQ (N=1), ASPR (N=1)]
	▪ Data Capacity for Patient-Centered Outcomes Research through Creation of an Electronic Care Plan for People with Multiple Chronic Conditions [two awards dispersed: AHRQ (N=1), National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) (N=1)]
	▪ Developing a Strategically Coordinated Registry Network to Support Research on Women's Health Technologies (WHT-CRN) [three awards dispersed: FDA (N=1), NLM (N=1), ONC (N=1)]
	▪ Development of a Natural Language Processing Web Service for Public Health Use [two awards dispersed: CDC (N=1), FDA (N=1)]
	▪ Enhancing Data Resources for Researching Patterns of Mortality in Patient Centered Outcomes Research: Projects 1–4 -four awards dispersed: CDC (N=2), CMS (N=1), FDA (N=1)]
	▪ Harmonization of Various Common Data Models and Open Standards for Evidence Generation [five awards dispersed: FDA (N=1), NCI (N=1), NIH National Center for Advancing Translational Sciences (N=1), NLM (N=1), ONC (N=1)]
	▪ Technologies for Donating Medicare Beneficiary Claims Data to Research Studies [two awards dispersed: CMS(N=1), NIH (N=1)]

Appendix C. 2017 Evaluation Gap Area Criteria

2017 Evaluation Results: Guidance on the five strategic areas of focus for the future of the portfolio was informed by stakeholder feedback. Based on the stakeholder feedback, the following criteria were used to assess how the OS-PCORTF awards address the strategic gap areas identified by the 2017.[3]

- **Implementing Standards:** Develop best practices to develop, implement, and maintain data standards so that health care and research institutions can reduce the time and costs incurred when implementing and updating standards.
  - Awards that develop new content or information exchange standards
  - Awards that support access via repositories or portals to validated value sets and CDEs and current data and vocabulary standards
  - Awards that develop CDEs
  - Awards that harmonize CDMs
  - Awards that support structured data capture
  - Awards that result in standards frameworks and implementation guides
  - Awards that pilot-test standards and implementation guides
  - Awards that develop and/or pilot standards facilitate patient data donation for research
- **Enhancing Data Governance:** Additional effort is needed to address ongoing barriers to increased data capacity. Although this issue remains challenging, it is critical to the efficient use of the research-oriented data infrastructure across individual and organizations' boundaries of control and ownership.
  - Awards that develop policies or frameworks that specify who can access data (authorization) and for what purpose, based on existing law and regulations.
  - Awards that develop and/or pilot-test data provenance standards
- **Improving Data Quality:** Promote a focus on data quality and increase the quantity and accessibility of electronic health data to improve the efficiency and effectiveness of PCOR; also support core functions and improvements in data interoperability.
  - Awards that focus on improving data completeness
  - Awards that address issues around assessing the fitness-of-use of data (e.g., "fit-for-purpose" metadata standards); awards that address issues of data validity and reliability
  - Awards that develop and/or pilot approaches to analyzing unstructured data
  - Awards that support data linkages between clinical and claims data
- **Balancing Access with Enhancing Privacy and Security**: Spur strategies that enhance privacy and security and inform how research and health care entities can better balance data access with security. Strategies include employing innovative technologies that offer researchers access to data, securely and privately, as well as educating the public about the benefits of making available their anonymous health care data.
  - Awards that develop and/or pilot security standards

    - Awards that develop and/or pilot standards for securely accessing clinical data (e.g., APIs, data access standards)
    - Awards that develop and/or pilot standards facilitate patient data donation for research
    - Awards that develop and/or pilot standards to facilitate patient access to data through standards
- **Disseminating Research Findings:** Improve mechanisms for dissemination of OS-PCORTF-sponsored research so that stakeholders within and outside of HHS can better gauge federal efforts to build data capacity for PCOR.
    - Awards that have a defined plan for publishing the results of their work
    - Awards that partner with non-federal organizations to disseminate the findings from their work
    - Awards that support workforce or researcher education

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