

Transitioning to value-based care: Clinical data registries

Despite the proven ability of clinical data registries to meaningfully improve patient care as well as statutory obligations to promote and incentivize the use of clinical data registries, current Medicare physician payment policies and processes have created obstacles for their successful use in the program. The Centers for Medicare & Medicaid Services' (CMS) clinical data registry approval process under the Merit-based Incentive Payment (MIPS) program is complex and cumbersome, and the lack of accessible cost data inhibits progress toward true value-based care. As a result, physicians' ability to leverage their participation in these quality improvement efforts for MIPS and engage in continuous learning has been limited.

For example, clinicians who practice in larger institutions have little control over decisions about quality measure selection or about participation in a clinical data registry (known as a "Qualified Clinical Data Registry" or "QCDR" within MIPS). As a result, many specialty-specific QCDRs and QCDR measures are underutilized. Further, CMS continues to use a flawed approach to measuring the health IT focused "Promoting Interoperability" component in MIPS that prohibits physicians' use of innovative IT technology. The approach does not grow with new technological innovations (many of which can be leveraged through a clinical data registry) that can drive the industry forward.

Recommendation

Well-designed clinical data registries, with access to claims data, incorporate all the elements of value-based care under MIPS: quality, cost, health information technology, and improvement activities. Yet, CMS fails to recognize their overarching benefits. To address this, Congress should require CMS to grant automatic credit for requirements in the "Promoting Interoperability" and "Improvement Activities" MIPS categories for physicians or practices that participate in a clinical data registry.

A physician or practice should also be able to satisfy the requirement to meet the "Promoting Interoperability" category by attesting to using certified electronic health record technology or interacting technology products (like a laboratory or radiology information system), participation in a clinical data registry, or other less burdensome means. Further, Congress should instruct CMS to consider incentivizing the use of innovative technology and clinical data registries in establishing standards for all MIPS categories and activities.

What is a clinical data registry?

A clinical data registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition or exposure, and that serves one or more stated scientific, clinical or policy purposes. Registries provide timely feedback to participating clinicians on patient outcomes and the quality of care they provide to patients. The dynamic feedback provided by registries allows physicians to identify weaknesses and implement changes (often in or near real-time) that create high-value care and track improvements over time.¹ Many medical specialty societies with clinical registries are using the data to inform evidence-based research and the development of clinical guidelines and decision support tools.

1. Registries for Evaluating Patient Outcomes: A Users Guide 4th Edition.

<https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/registries-evaluating-patient-outcomes-4th-edition.pdf>

Benefits of registry participation

Stakeholders may benefit from the value of registries in various ways.

Physicians: Registries can collect data about disease presentation and outcomes on large numbers of patients rapidly, thereby producing a real-world picture of disease, current treatment practices and outcomes. For a physician practice, a registry might provide data that can be used to assess the number of real-world procedures performed using a specific new technique or technology, to examine the degree to which clinicians are managing a disease in accordance with evidence-based guidelines, to evaluate the improvement in quality of life for patients following therapeutic management, to focus attention on specific aspects of a particular disease that might otherwise be overlooked, or to provide data for clinicians to compare themselves with their peers.

Patients: A registry may increase understanding of the natural history of a disease, contribute to the development of treatment guidelines, or facilitate research on treatment. A registry often actively works to engage patients and collect data directly from them to assist in shared decision making. Many registries also publicly report the data.

Payers: Registries can provide detailed, longitudinal information from large numbers of patients on how procedures, devices, or pharmaceuticals are used and on their effectiveness in different populations. This information may be useful for determining coverage policies or informing or supporting value-based care programs.