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Fast Focus

Clinical Data Registries

The Advancement of Clinical Data Registries

Registries work as databases to hold and organize healthcare data. They are tasked with evaluating and improving clinical outcomes for a patient population within specific defined measures. Professional associations, specialty societies, research and patient foundations, and government organizations often use clinical registries for patient data management, aggregation, and analysis.

Registry data management offerings are advancing in lockstep with healthcare's new technological capabilities. For example, registries now rely on intelligent automation and analytics to enhance data storage, expand data aggregation, and evolve the industry in improved care.

Furthermore, multiple types of registries are now available to any healthcare stakeholder that requires the safe management of data—payers, providers, physicians, pharmaceutical companies, and more. Using this data, registries encompass quality initiatives and improved patient outcomes alongside support for Merit-based Incentive Payment System (MIPS) reporting requirements.

This Fast Focus Brief explores the role of clean, accurate, and complete patient data to foster sustainable registry success in healthcare.

What are the different types of clinical data registries?

Patient Registry
- Analyzes and tracks patient health status and care received based on a specific disease or condition.
- Aggregates data with the goal of longitudinally reviewing outcomes, best practices, treatment guidelines, and support for research development.

Specialty Registry
- Focuses on the advancement of care and outcomes across medical specialties or sub-specialties.
- Aims to develop new quality improvement parameters and support tools to advance research and care.
- Allows providers, within Qualified Clinical Data Registries (QCDRs), to submit reports to CMS for MIPS.

Population Registry
- Focuses on capturing the health journeys across entire patient populations by tracking both specialty care and specific diseases or conditions.
- Tracks data according to demographics, geography, disease, or condition.

Device Registry
- Specifies the evaluation of medical device effectiveness, safety, and value—as data collection from various devices based on procedures or conditions, or support for market surveillance.

Payer Registry
- Established by payers for internal advancements to improve outcomes and reduce costs.
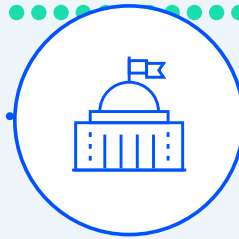- Tracks geography or specialty.

Clinical Data Registry Challenges

Unstable Funding

Inefficiency

Regulatory Alignment

Data Management

Registries face many challenges, including unstable funding, inefficiencies in harmonizing data, and mandatory regulatory alignment. But one of the most difficult challenges involves managing vast amounts of data while also maintaining quality and accuracy.

Registries must have reliable and accurate data to produce advancements in the industry and support their members. MRO's unique and proven capabilities address registries' most common challenges with specific focus in four areas: Physician Practice Management, Standardized Data, Data Management and Data Reliability.

MRO's Four Pillars of Success with Data Capabilities

Data Management

MRO delivers decades of expertise managing patient data complexities including extraction, standardization/aggregation, and clinical insights based on analysis, data visualization, and benchmarking.

Complex processes produce complex challenges. Registries depend on MRO's experience to:

- Manage data for a vast number of patients
- Navigate disparate data sources
- Coordinate with numerous physicians and practices

Physician Practice Management

Registries serve the needs of multiple medical groups that may include hundreds of unique providers and physician practices. Many of these practices lack sufficient time, staff, or funding needed to meet mandatory quality reporting requirements.

MRO provides data technology and services to bridge those gaps. We partner with both registries and physician practices to continually ensure data is accurate, complete, and compliant with quality reporting mandates.

Ongoing versus retrospective data analysis helps practices continually monitor and improve quality scores. This includes practice recommendations to improve data capture.

Standardized Data

MRO's capabilities offer the ability to extract and aggregate vast amounts of data across systems regardless of format. Varying terminology for care processes is standardized to produce new levels of data consistency. MRO ensures registries ingest patient data correctly across stakeholders for downstream requirements and processes.

Data Reliability

Alongside proven data standardization processes, MRO improves data reliability for registries. Data errors are reduced to mitigate negative impacts on patient outcomes, research findings, clinical guidelines, and more.

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New Requirements to Balance Sustainability with Interoperability

2024 marks the heightened necessity for registries and their practices to prioritize data interoperability. Reliable data transfer across the healthcare ecosystem is no longer a "nice to have" option. Registries must be capable participants in clinical data exchange.

Registries produce effective data exchange and improve patient outcomes in partnership with MRO. These efforts also support compliance with regulations such as the use of APIs for prior authorization, prohibitions against data blocking, updated SDOH data formatting requirements, and health IT system certifications.

Savvy registry leaders work with MRO to ensure each registry's sustainability, efficiency, and return on financial investment. They are on board with advanced technology platforms that comply with reporting and compliance needs while ensuring that current or newly implemented technology platforms make every outlay of time, money, and effort count.

Seven Best Practices to Improve Clinical Data Integrity in Registries

Data is the new healthcare currency. And data exchange through improved interoperability is the new standard of care. To play an active role in the safe and secure sharing of accurate patient information, here are seven best practices for registries to consider.

- **Extract data from multiple systems**
- **Process data through mapping and normalization against all reporting metrics**
- **Capture patient-reported outcomes (PROs)**
- **Maintain a clean and efficient database**
- **Display data in dashboards**
- **Package and send data for seasonal and timely mandatory reporting**
- **Work alongside registry customer service teams in training and onboarding, to monitor and improve quality scores and provide recommendations to improve data capture**

How to Make Participation a Win-Win for Clinical Data Registry Participants

Registries face **major difficulties** in persuading participants to join and enter the patient data required for participation. Physician practices and other participants continually ask, "What's in it for me?"

Balancing data input needs with burgeoning patient volumes and other competing priorities is not easy for understaffed physician practices and medical groups. Here are five strategies to encourage initial and ongoing physician participation in your clinical registry.

- Specify how the practice will benefit from joining the clinical registry.
- Highlight tangible benefits such as improved patient outcomes and potential financial incentives. Emphasize the role of the registry in identifying best practices and clinical guidelines that directly benefit patient care.
- Ease staff burdens by streamlining the data entry and quality reporting process.
  - Registries facilitate the submission of data for programs like MIPS by collecting and organizing necessary data. Automated EHR data extraction and aggregation ensures data accuracy and minimizes workload, making it easier to meet quality reporting requirements.
- Benchmark data against their peers to produce better practice insights.
  - Registries can allow participants to compare their performance with that of their peers. Benchmarking can identify areas for improvement and highlight successful strategies employed by other practices.

- National Committee for Quality Assurance (NCQA) and Office of the National Coordinator for Health Information Technology (ONC Health IT) certifications.
  - These certifications assure participants of the quality, security, and interoperability of the data collected, and reassure them about the reliability of the registry.
- Document progress toward greater interoperability and clinical data exchange.
  - Demonstrate how participation in the registry contributes to broader goals of interoperability and seamless clinical data exchange and how these improvements enhance their ability to coordinate care and improve overall patient outcomes.

Conclusion

Data is essential to registry sustainability throughout research, reporting, and outcome-driven initiatives. Clean, trusted, accurate data brings actionable insights that improve all outcomes.

> "We use MRO to manage the operations of two clinical data registries. Their platform helps us ensure secure and HIPAA-compliant data transfer, which is vital for advancing our research in cardiovascular disease and diabetes. By aggregating vast amounts of data from numerous practices, we access almost every EHR system, facilitating efficient data collection. And our practices gain valuable benchmarks for better reporting and quality of care delivery."
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> **Nicole Darden, Registry Product Manager, Veradigm**

Consider a partnership with MRO to extract, map, normalize and visualize the data vital for your organization and to ensure the utmost quality and accuracy needed to meet your aims.

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