

Patient Registries: A New Pillar of Modern Care

Analytics are almost as integral to healthcare as medicine. A vital resource for patient data are registries, which enable hospitals, health systems and physicians to assess the effectiveness of their practices and advance efforts to deliver data-driven, evidence-based care. Recent developments have elevated the importance of patient registries and accelerated their growth.

- Chronic disease registries are now more widely used for government and insurance plans to allocate resources and reward or penalize hospitals and providers based on outcomes.¹
- Registries are becoming essential for integrated care models, chronic care management and wellness initiatives. About 75% of hospitals on Hospitals & Health Networks Most Wired list use a disease registry to manage gaps in care across a population.²
- As part of a new bill signed into law in 2015, measures used by qualified clinical data registries will be allowed for assessing quality performance for physicians' Merit-Based Incentive Payment System starting in 2018.³
- De-identified patient records for roughly 1.1 million diabetics are the basis of the Surveillance, Prevention, and Management of Diabetes Mellitus DataLink (SUPREME-DM) registry shared between providers to develop more comprehensive prevention and treatment strategies.⁴

This white paper will examine why patient registries are on the rise and how hospitals and health systems are taking advantage of the actionable patient data they provide. It will discuss the growth of different types of registries and the challenges hospitals face in submitting quality information. Lastly, it will explore new advances in real-time registry reporting through concurrent reviews that enable quality assurance leaders to identify and change behavioral outliers while the patient is still in the hospital.

By the end of 2016, 85% of Medicare hospital fee-for-service payments are expected to be tied to quality or value through programs like the Hospital Value-Based Purchasing Program or the Hospital Readmissions Reduction Program.⁵

Patient Registries 101

The National Institutes of Health defines a registry as a collection of information about individuals, usually focused around a specific diagnosis or condition.⁶ According to the Agency for Healthcare Research and Quality, a patient 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.⁷

Although most registries are comprised of patients defined by the same diagnosis of a disease or condition, such as cystic fibrosis or heart failure, health services registries consist of patients who have had a common procedure,

clinical encounter or hospitalization. Many hospitals have their own registries and pool their data with other hospitals in studies that compare patterns of care among providers, population subsets, or geographic regions. Although no definitive data is available on exactly how many patient registries exist, the U.S. government's ClinicalTrials.gov has more than 800 patient registries, which, according to AHRQ's head of technology assessment, probably represent just the "tip of the iceberg."⁸

Multiple Purposes and Benefits

An appropriately designed and conducted registry provides hospitals, health systems and physicians with invaluable scientific information about the effectiveness, safety, and quality of the healthcare service or intervention being studied. This information is used for research, quality management and improvement, facility planning and marketing, monitoring patient outcomes, program development, disease prevention and surveillance, survival data, compliance of reporting standards, evaluation of the results of treatment, and national accreditation standards.

Hospitals and physicians can use the registries to monitor outcomes and study best practices in care or treatment.⁹ Physicians may use them to pursue specific research, and hospitals' participation in these databases may provide more opportunities to be involved in clinical trials.

Patient registry data also can help hospitals and state health agencies learn about population behavior patterns and their association with disease development. It can be used, for example, to identify those in its population who use tobacco, or to target those over 50 who have not had a colonoscopy or immunization. Some experts have called disease registries, EHR use and patient portals the three pillars of the IT infrastructure needed to improve population health.¹⁰

Why Registries are on the Rise

Two related developments have fueled hospital participation in registries:

- The shift to pay-for-performance and value-based reimbursement models that put providers at risk for financial losses if they don't meet cost and quality targets.
- An intense focus on evidence-based health care as the key driver of quality.

For example, the government as well as commercial payers may require participation in a quality monitoring or health system surveillance registry for reimbursement, differential payments, or patient referrals under various programs such as the CMS's public reporting initiative or its Coverage with Evidence Development programs. Registry participation has been required to qualify for payment for various procedures and devices, including implantable cardioverter defibrillators, bariatric surgery and positron emission tomography scans.¹¹

Some registries also collect and report mandatory hospital performance or quality-of-care data, which enable hospitals to demonstrate compliance standards. For example, a number of registries allow hospitals to document their performance to meet the Joint Commission requirements for hospital accreditation. Many registries measure the quality of patient care against various payer and government standards.

Other reasons for hospitals or health systems to participate in a patient registry are to burnish its reputation in certain disease areas or attract and retain elite physicians. High scores in patient registries can have a positive effect on physician recruitment and patient preferences.

Tracking and Managing Chronic Diseases and Patient Populations

A key function for all types of registries is generating evidence that can then be used to inform better decision-making in today's data-driven healthcare world. As the practice of medicine shifts from episodic care to a more holistic, integrated approach, this information is essential for two priority objectives – managing chronic disease conditions and improving the overall health status of patient populations.

Disease registries can be used to track clinical patient data across a wide range of the most common—and often preventable—chronic health conditions, including obesity and diabetes, as well as others that can be more effectively managed, such as hypertension, arthritis, and heart disease. According to the Health Resources and Services Administration, registries can help hospitals and physicians care for patients with chronic condition by providing:

- Reports at the point of care to remind practitioners of appropriate tests and interventions as well as record-updating responsibilities
- Information to assess progress in patient improvement or other areas of concern
- Exception reports to identify patients due for care as well as those whose results do not fall within acceptable ranges
- Stratified population reports to guide program development¹²

According to the vice president for quality management and research at the American Medical Group Association, one of the 12 steps for creating a successful ACO is to develop disease registries that include anyone with chronic disease and follow them to determine whether they are complying.¹³ As the former medical director for quality improvement for the American Academy of Family Physicians has noted, “the true value of a registry is that diseases can be prevented not just managed.”¹⁴

“A robust clinical registry can tell doctors in real time what medications work well and which are harming patients.”¹⁵

- Michol Cooper: M.D., Ph.D., Johns Hopkins University School of Medicine

Data Collection and Quality

The usefulness of any clinical registry depends directly on the quality of the data it collects. Registries should be designed and implemented with sufficient safeguards, rigor and transparency to ensure that their primary functions are well served and will not lead to erroneous conclusions.

However, a recent study by Johns Hopkins researchers concluded that most U.S. clinical registries that collect data on patient outcomes are substandard. The study's senior investigator noted that “our results highlight the acute need to improve the way clinical outcomes data are collected and reported.”¹⁶ Critical factors in the ultimate quality of the data include:

- How data elements are structured and defined
- How personnel are trained
- How data problems are handled (e.g., missing, out-of-range, or logically inconsistent values)¹⁷

Data completeness is another important component of registry quality, which can be affected by how closely data collection is integrated with clinical care as well as the knowledge and skills of those entering data. Interoperability between electronic health records and registries facilitates data and clinical care integration. For example, through its EHR-integrated registries and its highly skilled team, Lancaster (Pa.) General Health has developed disease-based dashboards to closely follow covered lives in its ACO. These tools empower their care teams to create effective care transitions, manage gaps in care, reduce preventable admissions and prevent readmissions.¹⁸

Many threats to data quality, including variability in case completeness and data accuracy, may be overcome with careful registry planning and design, using properly trained personnel for data entry, and applying mechanisms to assess and improve data quality.¹⁹ More information about the methods and operational practices needed to design and implement a registry are available from the Agency for Healthcare Research and Quality (AHRQ) in its guide entitled “Registries for Evaluating Patient Outcomes: A User’s Guide.”²⁰

Medical Registrars: Guardians of Data Quality

Another prerequisite for data quality is the proper abstraction of information from medical records to ensure that registry submissions have all the necessary data. For most registries, this must be done by certified medical registrars who manage and analyze clinical information for the purpose of processing, maintaining, compiling and reporting health information.

Registrars must have highly specialized clinical and technical knowledge and skillsets to be able to maintain complex disease-related data collection systems in compliance with medical, administrative, ethical, legal, and accreditation requirements of the health care delivery system. They essentially act as guardians at the gate to make certain data submissions to registries are accurate, complete and properly formatted.

Not surprisingly, as the number and types of clinical registries continue to grow, hospitals are finding that the talent pool of qualified medical registrars is rapidly shrinking. For example, many are reporting backlogs and related problems in their cancer registries and acknowledge the difficulty of training qualified professionals.²¹



Good Practices to Ensure Data Quality

The AHRQ User’s Guide to patient registries includes the following Basic Elements of Good Practice regarding data quality assurance:

- Data are reasonably complete.
- Reasonable efforts have been expended to assure that appropriate patients have been systematically enrolled and followed in as unbiased a manner as possible.
- Reasonable efforts have been devoted to minimize losses to follow-up.
- Data checks, well qualified personnel, are employed using range and consistency checks.

Further exacerbating this challenge are the varying levels of acuity at a growing number of registries such as the Vermont Oxford Network (VON) for neonatal care, which require a specific group of abstractors for each level. As registries demand even more rigorous credentialing standards to ensure professionalism, the gap between supply and demand for medical registrars will continue to widen.

Outsourcing Registry Abstraction

In the past, hospitals might typically assign responsibility for registry abstraction to their nurses or quality managers, usually on a part-time basis. Today, however, attaining and maintaining a high level of proficiency in registry abstraction demands a full-time commitment. Each registry has unique credentialing requirements, and registrars often must pass annual tests to maintain their certification. They also need continuing education to stay current with best practices.

To address the growing demand for qualified registrars, more and more hospitals are turning to outsourcing services for registry abstraction such as those from Q-Centrix, the largest and fastest growing abstraction services company in the U.S. The benefits of outsourcing include:

- Enables hospital nurses and quality managers to be more useful on the floor caring for patients or monitoring quality practices
- Increases clinical confidence in data accuracy derived from a third-party, neutral abstracting organization
- Reduces registry data variability and improves quality, which increases practitioner and staff productivity and leads to more effective changes in protocol and policies
- Eliminates staff multi-tasking, which undermines efficiency and can result in a 40% drop in productivity
- Leverages the expertise and skills of experienced medical registrars at the top of their game — Q-Centrix professionals have completed more than 5 million quality abstractions

Best Practices: Concurrent Data Review for Patient Registries

CMS continues to shift its focus to outcomes measures and has set a goal of tying 50% of all traditional Medicare payments to quality or value by 2018 through new payment models, including ACOs.²² With hospitals and health systems at higher risk, their ability to access and use actionable data to provide quality patient care must quickly become a core competency.

One effective strategy hospitals are using to accomplish this goal is to take advantage of services that review registry data in real time. Registry submissions include hundreds of data elements – including quality metrics – yet often some of these elements are missing and not available for use at the time of abstraction. Many quality fallouts are related to documentation errors and omissions.

Concurrent review of patient charts and other registry data can help prevent these problems. For example, Q-Centrix registry specialists review charts in real time to identify and resolve potential quality fallouts before the patient leaves the hospital.

“The need for disease-specific data is so great and it will only grow.”

- Karlene Strayer: Manager, Quality Data, Mississippi Baptist Medical Center

Do You Want More Value from Your Patient Registries? Talk to Us. Visit www.q-centrix.com or call us at (603) 294-1145.

Registries are an investment in the infrastructure of healthcare delivery and require innovative and visionary leadership to support the vital role that they play in improving healthcare quality.²³ Q-Centrix provides the support you need to maximize your registry ROI. We have the industry's largest and broadest team of registry specialists who help our partner hospitals ensure data quality for more than (number) registries.

We offer flexible services with no long-term obligations and can provide you with a complimentary savings analysis comparing your internal expenses with the costs of a Q-Centrix partnership. Talk to us to learn more about how our customized registry abstraction program can help your hospital take full advantage of registries as valuable resources to improve your quality and outcomes.

¹ <http://www.diabetesincontrol.com/chronic-disease-registries/>

² <http://www.hhnmag.com/articles//3682-disease-registries-prove-useful-in-improving-population-health>

³ <http://www.fiercehealthit.com/story/sgr-passage-reactions-positive-hit-stakeholders-questions-loom/2015-04-15>

⁴ <http://www.fiercehealthit.com/story/better-data-standards-registries-key-value-based-healthcare/2012-06-25>

⁵ <https://www.advisory.com/daily-briefing/2015/01/27/hhs-aims-to-pay-30-of-medicare-dollars-through-alternate-models-by-2016>

⁶ <http://www.nih.gov/health-information/nih-clinical-research-trials-you/list-registries>

⁷ <http://www.ncbi.nlm.nih.gov/books/NBK164514/>

⁸ <http://www.nature.com/nm/journal/v17/n1/full/nm0111-4a.html>

⁹ <http://www.ncbi.nlm.nih.gov/books/NBK164514/>

¹⁰ <http://www.beckershospitalreview.com/accountable-care-organizations/4-essential-factors-for-population-health-accountable-care.html>

¹¹ <http://www.ncbi.nlm.nih.gov/books/NBK208617/>

¹² <http://medicaleconomics.modernmedicine.com/medical-economics/content/tags/chronic-care/registries-powerful-tools-track-manage-chronic-disease>

¹³ <http://www.beckershospitalreview.com/hospital-physician-relationships/12-steps-to-create-a-successful-aco-from-a-medical-groups-perspective.html>

¹⁴ <http://www.hhnmag.com/articles//3682-disease-registries-prove-useful-in-improving-population-health>

¹⁵ http://www.hopkinsmedicine.org/news/media/releases/study_questions_quality_of_us_health_data

¹⁶ http://www.hopkinsmedicine.org/news/media/releases/study_questions_quality_of_us_health_data

¹⁷ <http://effectivehealthcare.ahrq.gov/ehc/products/21/12/PatOutExecSumm.pdf>

¹⁸ <http://www.hhnmag.com/articles//3682-disease-registries-prove-useful-in-improving-population-health>

¹⁹ <http://circ.ahajournals.org/content/123/19/2167.long>

²⁰ <http://effectivehealthcare.ahrq.gov/ehc/products/21/12/PatOutExecSumm.pdf>

²¹ <http://health-information.advanceweb.com/Columns/Registry-Perspectives/Cancer-Registry-Workforce-Shortage-Still-Mounting-Fast-as-Demand-Accelerates.aspx>

²² <http://www.hhs.gov/about/news/2015/01/26/better-smarter-healthier-in-historic-announcement-hhs-sets-clear-goals-and-timeline-for-shifting-medicare-reimbursements-from-volume-to-value.html>

²³ <http://circ.ahajournals.org/content/123/19/2167.long>