

FACTS CLINICAL REGISTRIES

OVERVIEW

A “clinical registry” is a database of health information on specific clinical conditions, procedures or populations. The data collected in a registry captures clinically important events relevant to a particular population or condition. Registries can be integrated with electronic health records (EHRs) to directly support evaluation of care delivery and patient outcomes. Registries can broaden knowledge of clinical service patterns, processes and patient outcomes and can capture valuable, real-time patient data that is not present in an administrative record, which typically only contains claims data or billing information about procedures and services.

USES OF CLINICAL REGISTRIES

Clinical registries provide important mechanisms to monitor patterns of care and progression of disease, evaluate healthcare effectiveness and safety, and improve clinical outcomes in a real world setting.

Surveillance of Healthcare Systems. Registries are an efficient way to monitor trends in the use of certain procedures and the prevalence of certain conditions.¹ Today, clinical registries are used to:

- Assess the progression of a disease, evaluate treatments utilized at various stages of disease, and observe treatment outcomes and adverse events;^{2,3,4,5}
- Evaluate trends in healthcare usage and the provision of medically necessary care (including underuse, overuse and misuse);¹
- Monitor the impact of prevention efforts⁶ and public health awareness campaigns;⁷
- Analyze referral and diagnosis patterns;¹
- Describe patient population demographics and provider characteristics;² and
- Track incidence of health events and recurrent events.^{2,8}

Surveillance of Underrepresented Populations.

Clinical registries play an essential role in providing meaningful, actionable data about the healthcare needs and the services used by populations of patients that traditionally have been underrepresented in epidemiological studies and clinical trials, including racial and ethnic minorities⁹, women¹⁰, the elderly¹¹, individuals with multiple co-morbidities,^{1,12} and individuals with rare diseases.¹³ With data from a clinical registry, researchers can:

- Identify and evaluate healthcare disparities within a patient population;
- Examine underrepresented populations and their access to healthcare services;
- Investigate disease progression and healthcare utilization in a particular subpopulation, and the costs for treating particular groups; and
- Collect data on gender, race, ethnicity, language and other health indicators.

By collecting and tracking treatment patterns over time, this data can be used to expose disparities in care for minority populations, as well as address them. The American Heart Association/American Stroke Association’s Get With The Guidelines® (GWTG)-Stroke registry, for example, has documented poor quality in stroke care for black patients as compared to white and Hispanic⁹ and GWTG-Coronary Artery Disease (CAD) (now called ACTION Registry-GWTG) was associated with an elimination of disparities in the quality of care for acute myocardial infarction (AMI) regardless of race or ethnicity.¹⁰

Measuring Quality & Safety. Registries are frequently used to evaluate and improve healthcare quality. Because a registry can continuously capture data, registries have the potential to identify unnecessary or inappropriate variation and drive quality improvement by creating a continuous feedback loop to pinpoint areas of poor quality. Other ways that clinical registries support quality and safety evaluation include:

- Monitoring adverse events related to particular therapies, drugs, or devices;^{5,14}
- Examining provider adherence to safety protocols and best practice guidelines;² and
- Enabling surveillance of the quality of care patients receive (e.g. tracking rates of re/admissions and, coordination of care post-discharge, orders for preventive care at discharge, etc.).^{1,8,5}

THE ASSOCIATIONS’ REGISTRIES

As part of its commitment to improving patient care for cardiovascular disease (CVD) and stroke, the American Heart Association/American Stroke Association has developed a number of quality improvement programs that include clinical registries. The GWTG suite of programs uses registries to aggregate patient care data and generate real-time reports for providers that assess their performance compared to national benchmark data.

Get With The Guidelines-Stroke. GWTG-Stroke, was developed by the American Heart Association/American Stroke Association in 2001 as a national stroke registry and performance improvement program for hospitals¹⁴ to improve the quality of care and outcomes for patients hospitalized with stroke and transient ischemic attack (TIA).¹⁵ The registry contains almost 2.5 million stroke/TIA patient encounters presenting to more than 1,700 hospitals nationwide.¹⁶ Due to its size, national scope, duration, and prospective collection of patient level data, it provides a unique opportunity to investigate presenting characteristics, diagnostic testing, treatments, quality initiative adherence, and in-hospital outcomes in a broad cohort of patients.²

Acute Coronary Treatment and Intervention Outcomes Network Registry-Get With The Guidelines. ACTION Registry-GWTG is a national surveillance system for high-risk patients with AMI. Launched in 2007, the registry is a combination of two former leading national CAD registries: the National Cardiovascular Data ACTION Registry and the American Heart Association's GWTG-CAD Registry.^{17,18} The goal of the new registry was to create the largest and most comprehensive cardiovascular patient database in the U.S.¹⁹ The registry establishes the national standard for understanding and improving quality, safety and outcomes of care for patients with CAD.¹ Clinical data from this registry supports ongoing national surveillance, innovative research, and quality improvement efforts facilitating evidence-based AMI care by tracking presenting characteristics, diagnostic testing, treatments, and in-hospital outcomes in a broad cohort of hospitalized AMI patients.²⁰

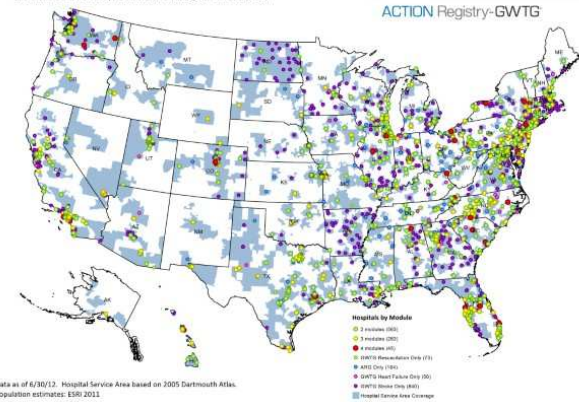
Other GWTG registries include those for Heart Failure and Resuscitation, as well as a newly launched joint outpatient program with the American Diabetes Association and the American Cancer Society called The Guideline Advantage.TM

THE ASSOCIATION ADVOCATES

We support the use of registries to improve quality of care and to help identify risk factors to reduce chronic diseases. Specifically, we:

- Urge policy makers to create federal, state and local CVD and stroke registries in order to monitor incidence and support the development of relevant quality improvement initiatives.
- Encourage policy makers to use patient-centered, evidence-based, broadly-adopted registries like GWTG to meet many of the quality improvement and reporting requirements of federal programs and those enacted in health reform.
- Encourage use of registries as an efficient data collection tool as part of payment and delivery reform initiatives.

Get With the Guidelines® - Stroke, Heart Failure, Resuscitation and ACTION Registry™-GWTG™ Hospitals
(Count: 2004; 77.6% population coverage as of 6/30/12)



¹ Reeves MJ et al. Quality of Care and Outcomes in Patients With Diabetes Hospitalized With Ischemic Stroke: Findings From Get With the Guidelines-Stroke. *Stroke*. 2010;41:1-9.

² Fonarow GC et al. Characteristics, Performance Measures, and In-Hospital Outcomes of the First One Million Stroke and Transient Ischemic Attack Admissions in Get With The Guidelines-Stroke. *Circ Cardiovasc Qual Outcomes*. 2010;3:291-302.

³ Benza RL, et al. Predicting Survival in Pulmonary Arterial Hypertension: Insights from the Registry to Evaluate Early and Long-Term Pulmonary Arterial Hypertension Disease Management (REVEAL). *Circulation*. 2010;122:164-172.

⁴ Dabelea D. The Value of National Diabetes Registries: SEARCH for Diabetes in Youth Study. *Curr Diab Rep*. 2010.

⁵ Parikh SV et al. Timing of in-hospital coronary artery bypass graft surgery for non-ST-segment elevation myocardial infarction patients results from the National Cardiovascular Data Registry ACTION Registry-GWTG (Acute Coronary Treatment and Intervention Outcomes Network Registry-Get With The Guidelines). *JACC Cardiovasc Interv*. 2010 Apr;3(4):428-30.

⁶ Schwamm, L H et al. Get With the Guidelines Stroke Is Associated With Sustained Improvement in Care for Patients Hospitalized With Acute Stroke or Transient Ischemic Attack. *Circulation*. 2009;119:107-115.

⁷ Diercks DB et al. Gender differences in time to presentation for myocardial infarction before and after a national women's cardiovascular awareness campaign: a temporal analysis from the Can Rapid Risk Stratification of Unstable Angina Patients Suppress Adverse Outcomes with Early Implementation (CRUSADE) and the National Cardiovascular Data Registry Acute Coronary Treatment and Intervention Outcomes Network-Get with the Guidelines (NCDR ACTION Registry-GWTG). *Am Heart J*. 2010 Jul;160(1):80-87.e3.

⁸ LaBresh KA et al. Hospital Treatment of Patients With Ischemic Stroke or Transient Ischemic Attack Using the "Get With The Guidelines" Program. *Arch Intern Med*. 2008;168(4):411-417.

⁹ Schwamm, LH, et al. Race/Ethnicity, Quality of Care, and Outcomes in Ischemic Stroke. *Circulation*. 2010;121:1492-1501.

¹⁰ Cohen, M G, et al. Racial and Ethnic Differences in the Treatment of Acute Myocardial Infarction. Findings from the Get With The Guidelines Coronary Artery Disease Program. *Circulation*. May 17, 2010

¹¹ Reeves MJ, et al. Quality of Care in Women With Ischemic Stroke in the GWTG Program. *Stroke*. 2009;40:1127-1133.

¹² Fonarow GC et al. Age-Related Differences in Characteristics, Performance Measures, Treatment Trends, and Outcomes in Patients With Ischemic Stroke. *Circulation*. 2010;121:879-891.

¹³ Rothwell PM et al. Population-Based Study of Event-Rate, Incidence, Case Fatality, and Mortality For All Acute Vascular Events in All Arterial Territories (Oxford Vascular Study). *Lancet*. 2005;366:1773-1783.

¹⁴ Antiepileptic Drug Pregnancy Registry. *Massachusetts General Hospital*. <http://www.aedpregnancyregistry.org/>

¹⁵ American Heart Association: Get With the Guidelines-Stroke. Stroke Fact Sheet. 2009. available at: http://www.heart.org/idc/groups/heart-public/@wcm/@private/@hcm/@gwtg/documents/downloadable/ucm_310976.pdf

¹⁶ American Heart Association program statistics as of April 2013.

¹⁷ ACTION Registry-GWTG, American College of Cardiology Foundation, available at: <http://www.ncdr.com/webncdr/action/default.aspx>

¹⁸ ACTION Registry-GWTG, American Heart Association, available at: <http://www.americanheart.org/presenter.jhtml?identifier=3058774>

¹⁹ The American College of Cardiology Foundation's NCDR and the American Heart Association's GWTG Join Forces to Fight Heart Attacks. *AHA News Release*. May 1, 2007, available at: <http://www.newsroom.heart.org/index.php?s=43&item=415>

²⁰ Peterson ED et al. A Call to ACTION (Acute Coronary Treatment and Intervention Outcomes Network): A National Effort to Promote Timely Clinical Feedback and Support Continuous Quality Improvement for Acute Myocardial Infarction. *Circ Cardiovasc Qual Outcomes*. 2009 Sep;2(5):491-9.