FACTS
Get With the Guidelines-Stroke Registry

OVERVIEW
Stroke is the fourth leading cause of death and a leading cause of disability among Americans. In an effort to reduce the burden of stroke by improving the quality of care delivered to stroke patients, stroke registries have been developed to measure and track acute stroke care. Clinical registries, databases of health information on specific clinical conditions, procedures or populations, capture data on clinically important events relevant to a particular population or condition. They can be integrated with electronic health records (EHRs) to directly support evaluation of care delivery and patient outcomes. In 2001, the American Heart Association/American Stroke Association launched Get With The Guidelines (GWTG)® – Stroke, a performance improvement program for hospitals that uses a stroke registry to support its aims.

GWTG-Stroke collects patient level data on characteristics, diagnostic testing, treatments, adherence to quality measures, and in-hospital outcomes in patients hospitalized with stroke and transient ischemic attack (TIA). Collection of comprehensive, continuous stroke data supports data analysis and the development of interventions to improve stroke care. Currently, over 1,700 hospitals participate in GWTG-Stroke and data has been collected from over 2.5 million patient encounters for stroke.

The primary goal of GWTG-Stroke program is to improve the quality of care and outcomes for patients hospitalized with stroke and TIA. The GWTG-Stroke registry helps achieve this goal in a variety of ways, including:

- Enabling high caliber stroke research;
- Promoting stroke center designation;
- Supporting hospital level quality improvement; and
- Driving the creation of regional stroke systems.

ENABLING STROKE RESEARCH
The GWTG-Stroke registry is an important scientific resource for stroke research. Many studies about the quality of care and outcomes for stroke patients have been limited by the data available. For instance, they may examine only select populations, lack detailed data on diagnosis and care, or not have complete data on contraindications to recommended therapies. In contrast, as a result of its size, scope, duration, and prospective collection of patient level data, the GWTG-Stroke registry allows for the investigation of many of these factors, which improves the quality of the research. Additionally, the data collected by GWTG-Stroke is largely representative of the general population making research conducted using the registry applicable to populations in non-participating hospitals.

Hospital Participation in GWTG-Stroke Registry

PROMOTING STROKE CENTER CERTIFICATION
The Joint Commission’s (TJC’s) Stroke Center Certification programs, developed in collaboration with American Heart Association/American Stroke Association, recognize centers that have made exceptional efforts to foster better outcomes for stroke care. Primary Stroke Center designation, launched in 2003, identifies facilities that deliver care based on Brain Attack Coalition recommendations, support patient self-management, tailor treatment to individual needs, follow evidence-based guidelines, support the flow of information across care settings, and continually improve care. Recognizing the significant differences in resources, staff and training that are necessary for the treatment of complex stroke cases, TJC and American Heart Association/American Stroke Association began certifying Comprehensive Stroke Centers in 2012 to identify for consumers those hospitals that have specific abilities to receive and treat the most complex stroke cases.

GWTG-Stroke can serve as the registry to fulfill certification requirements. Furthermore, participation in GWTG-Stroke supports stroke centers’ efforts to continually improve by allowing them to analyze data on care processes and patient outcomes.
SUPPORTING QUALITY IMPROVEMENT

By providing hospitals with timely feedback on their stroke care performance, the GWTG-Stroke registry supports hospitals’ stroke care quality improvement efforts. More specifically, data from the registry allows hospitals to identify problems with their stroke care, develop quality improvement interventions based on the identified problems, and monitor their progress after implementation of a chosen intervention. As a result, hospitals participating in the GWTG-Stroke program show improvement in adherence to stroke performance measures.\(^7\)

In addition to supporting overall stroke care quality improvement, the GWTG-Stroke registry can help hospitals reduce disparities in the care they deliver. Evidence suggests that not only are minorities at higher risk of suffering a stroke but they also receive lower quality of care and have worse health outcomes. Hospitals participating in GWTG-Stroke improved care for black, Hispanic, and white patients.\(^8\)\(^9\)\(^10\)

The GWTG-Stroke registry also helps hospitals fulfill the Centers for Medicare and Medicaid Services’ (CMS) requirements for quality improvement. As of fiscal year 2010, CMS required hospitals submitting Medicare claims for stroke to report whether they participate in a database registry for stroke care.\(^9\)\(^10\) CMS has suggested that reporting stroke care quality measures, such as those in GWTG-Stroke, could be required of Medicare-participating hospitals beginning in 2015.\(^11\)

DRIVING STROKE CARE SYSTEMS DEVELOPMENT

GWTG-Stroke can catalyze systems changes on a regional or statewide basis to promote a more comprehensive and coordinated approach to stroke care.

Regional participation in GWTG-Stroke can help illuminate problems that exist in the stroke system of care. For instance, data may show poor patient education about stroke symptoms, geographical differences in the quality of stroke care received, or problems with adherence to stroke treatment guidelines. The data can then catalyze stakeholders to find solutions to the challenges encountered. For example, data from Maryland’s stroke registry showed that some of the state’s hospitals were reluctant to give tPA – a drug used to treat thrombotic and embolic stroke – to stroke patients. Having identified this concern, stakeholders were able to investigate its cause and determined that these hospitals were wary of prepping tPA because of the drug’s cost. Consequently, they developed a system where hospitals can return unused tPA to the manufacturer; this has promoted the delivery of tPA to appropriate stroke patients.\(^12\)

The GWTG-Stroke registry can also support an EMS stroke diversion policy that requires the EMS to take suspected stroke patients to the nearest designated stroke center. Stroke registries can provide data to catalyze diversion policy implementation, support the hospital designation process, and monitor the effects of a diversion policy on stroke outcomes.

The GWTG-Stroke registry also supports the work of stroke advocates. Its data can show the need for funding for stroke programs, illustrate a problem that requires government action, or more generally, move stroke up in importance on a state’s policy agenda.

PARTICIPATION VARIES BY STATE

Participation in stroke registries like GWTG-Stroke varies substantially by region. Low participation in some areas reflects a variety of factors including a lack of state-level support, a competitive or autonomous health care culture, and financial barriers. Wider implementation of GWTG-Stroke and other stroke registries will support improved stroke care across the country.

THE ASSOCIATION ADVOCATES

The American Heart Association/American Stroke Association supports the use of registries to improve the quality of stroke care and to help identify risk factors for the disease. Specifically, we:

- Encourage policy makers to use patient-centered, evidence-based, broadly-adopted stroke registries like GWTG-Stroke to meet the quality improvement and reporting requirements of federal programs and those enacted in healthcare reform.
- Encourage state officials to establish stroke registries to support high quality stroke systems of care and mandate reporting to them.

3 American Heart Association program statistics as of May 2013.
9 Medicare Program; Changes to the Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals and Fiscal Year 2010 Rates; and Changes to the Long-Term Care Hospital Prospective Payment System and Rate Years 2010 and 2009 Rates. 74 Fed. Reg. 49866 (August 27, 2009).
11 Medicare Program; Proposed Changes to the Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals and the Long-Term Care Hospital Prospective Payment System and Fiscal Year 2012 Rates. 76 Fed. Reg. 51633 (August 18, 2011).
12 Interviews with AHA state staff.