Creating, Implementing, and Evaluating Stroke Registries

The American Heart Association’s Position

- Policy makers must create federal, state, and local stroke registries to collect data on incidence rates and outcomes, understand existing gaps in stroke treatment, and support the development of relevant quality improvement initiatives.
- Policy makers must seek and utilize the leadership and consensus if an independent or state-sponsored stroke task force in the establishment, implementation, and evaluation of stroke registries.
- Policy makers must use patient-centered, evidence-based, broadly-adopted stroke registries like Get With the Guidelines to meet many of the quality improvement and reporting requirements of federal programs and those enacted in health reform.
- State laws or regulations must mandate that hospitals submit data to stroke registries as part of stroke center designations.
- States must provide adequate funding and oversight to assist hospitals in stroke registry participation.
- Stroke registries must be encouraged as efficient data collection tools for payment and delivery reform initiatives.
- Stroke registries must play an essential role in providing impactful data on stroke care in underserved populations.
- Patient EHRs must be fully-integrated with stroke registries.
- Strong, HIPAA-compliant confidentiality policies must be enacted and enforced to protect patient data that is submitted to stroke registries.
- Stroke registry data must only be used for quality improvement, and must not, therefore, be publicly available.
- Get with the Guidelines – Stroke is the American Heart Association’s collaborative performance improvement program, demonstrated to improve adherence to evidence-based care of patients hospitalized with stroke. Since 2003, over 2,000 hospitals have entered over 5 million patient records into the registry, thereby allowing these hospitals to treat stroke patients more adequately and accurately.

For more information and resources from the American Heart Association’s policy research department on stroke registries please visit: https://www.heart.org/en/about-us/policy-research.

Fast Facts:

1. Approximately 800,000 people in the US have a new or recurrent stroke each year.¹
2. In 2015, the estimated total cost for stroke in the US was $66.3 billion, and this is projected to increase to $143 billion by 2035.²
3. Analysis of 790 GWTG hospitals enrolled from April 2003 to July 2007 showed a 30.8% increase in IV tPA use for patients arriving within 2 hours of symptom onset.³
4. Ischemic stroke patients treated at Get With the Guidelines participating hospitals receive better, more comprehensive stroke care than patients treated at non-participating hospitals.⁴
5. Data within registries provide an ideal platform for randomized clinical trials, reducing both time and cost of prospective data collection.⁵

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