



Creating, Implementing, and Evaluating Stroke Registries

The American Heart Association's Position

- Policy makers should create federal, state, and local stroke registries to collect data on incidence rates and outcomes of strokes, to understand existing gaps in stroke treatment, and to support the development of relevant quality improvement initiatives.
- Policy makers should seek and utilize leadership and consensus in an independent or state-sponsored stroke task force in the establishment, implementation, and evaluation of stroke registries.
- Policy makers should use patient-centered, evidence-based, and broadly-adopted stroke registries like “Get With the Guidelines” (GTWG) to meet many quality improvement and reporting requirements of federal programs and those enacted in health reform.
- State laws or regulations should mandate that hospitals submit data to stroke registries as part of stroke center designations.
- States should provide adequate funding and oversight to assist hospitals in stroke registry participation.
- Stroke registries are efficient data collection tools for payment and delivery reform initiatives.
- Stroke registries should play an essential role in providing impactful data on stroke care in underserved populations.
- Patient electronic health records should 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 made 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.⁶ Since 2003, over 2,000 hospitals have entered more than 5 million patient records into their registries, thereby allowing these hospitals to treat stroke patients both more adequately and accurately.

Fast Facts:

1. Approximately 795,000 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 366 GTWG hospitals enrolled from April 2003 to December 2008 showed GTWG hospitals were able to discharge stroke patients to the home more quickly and had reduced mortality at 30 days and 1 year post-stroke compared to non-participating hospitals.³
4. Ischemic stroke patients treated at GTWG 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

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>.

Policy At A Glance: Stroke Registries

References

- ¹ Virani, S.S, Alonso, A., Benjamin, et al. Heart disease and stroke statistics—2020 update: a report from the American Heart Association. *Circulation* 2020, *141*, e139–e596.
- ² Khavjou, O.A., Phelps, D., Leib A. Projections of cardiovascular disease prevalence and costs: 2015–2035. American Heart Association. 2017. <https://healthmetrics.heart.org/wp-content/uploads/2017/10/Projections-of-Cardiovascular-Disease.pdf>.
- ³ Song S., Fonarow G.C , Olson D.M., et al. Association of Get With The Guidelines-Stroke Program Participation and Clinical Outcomes for Medicare Beneficiaries With Ischemic Stroke. *Stroke*. 2016;*47*(5): 1294–1302.
- ⁴ Howard G, Schwamm LH, Donnelly JP, et al. Participation in Get With The Guidelines–Stroke and Its Association With Quality of Care for Stroke. *JAMA Neurol*. 2018;*75*(11):1331–1337.
- ⁵ Bufalino VJ, Masoudi FA, Stranne SK, Horton K, Albert NM, Beam C, et al. The American Heart Association's recommendations for expanding the applications of existing and future clinical registries a policy statement from the American Heart Association. *Circulation*. 2011;*123*(19):2167–79. pmid:21482960
- ⁶ Fonarow, G.C., Reeves M.J., Smith E.E., 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. *Circulation: Cardiovascular Quality and Outcomes*. 2010;*3*(3):291-302