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TOPICAL REVIEWS

Twenty Years of Get With The Guidelines-Stroke: Celebrating Past Successes, Lessons Learned, and Future Challenges

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ABSTRACT

The Get With The Guidelines-Stroke program which, began 20 years ago, is one of the largest and most important nationally representative disease registries in the United States. Its importance to the stroke community can be gauged by its sustained growth and widespread dissemination of findings that demonstrate sustained increases in both the quality of care and patient outcomes over time. The objectives of this narrative review are to provide a brief history of Get With The Guidelines-Stroke, summarize its major successes and impact, and highlight lessons learned. Looking to the next 20 years, we discuss potential challenges and opportunities for the program.

Key Words: program development ■ quality improvement ■ quality of health care ■ registries ■ stroke ■ treatment outcome

The Get With The Guidelines (GWTG)-Stroke program or registry was developed with the principal aim of improving the quality of care and outcomes of patients hospitalized with acute stroke. Prior reports provide details of the program's origins, development, organization, and structure.[1–5] In brief, GWTG-Stroke began in 2001 when the American Heart Association (AHA) introduced a pilot quality improvement (QI) registry for stroke, based in part on the success of existing programs in coronary artery disease.[6,7] After becoming a national program in 2003, GWTG-Stroke grew rapidly. By August 2009, there were 1419 participating hospitals with data captured on 1 million stroke and TIA admissions.[3] In 2023, the registry now includes 9 million

patient records submitted by over 2600 participating hospitals, a level of growth that greatly exceeded expectations.

Several factors contributed to the establishment of a national QI-based stroke registry. A major driver were challenges in implementing intravenous (IV) thrombolysis (tPA) therapy, which had received FDA approval in 1995. Another driver was the development in 2004 of AHA strategic impact goals to reduce heart disease and stroke risk by 25% by 2020.[8] These goals would depend in part on secondary prevention medications (eg, antiplatelet, antihypertension, and statins), which were known to be suboptimal in many clinical populations.[9,10] Other factors that were foundational to establishing GWTG-Stroke include the AHA's Metro Stroke and Operation Stroke programs that began in 1998,[5] the Brain Attack Coalition recommendations in 2000 on primary stroke centers,[11] and funding from the Centers for Disease Control to establish the Paul Coverdell National Acute Stroke Registry in 2001.[12]

At the foundation of the registry is a data-driven approach to translate evidence and guidelines into clinical practice.[13] From its inception, the program was developed around the concept of a collaborative learning model that encourages hospitals to improve care by changing how they do things. Important features of the program include concurrent data collection and clinical decision support, as well as interactive learning modules and teleconferences that share data and QI strategies with hospitals.

WHAT ARE THE NOTABLE SUCCESSES AND OVERALL IMPACT OF THE GWTG-STROKE PROGRAM?

Improved Quality of Care Leading to Better Patient Outcomes

Analyses of data collected by GWTG-Stroke hospitals have demonstrated that participation in the program is associated with sustained improvements in the quality of care. Two early papers showed strong temporal trends in improved care processes and endorsed performance metrics.[2,3] Over the initial 5-years of the program, the IV tPA treatment rate among eligible patients arriving within 2 hours from the last known well increased from 42% to 73%, smoking cessation counseling increased from 74% to 88%, and DVT prophylaxis increased from 74% to 90%.[2] Treatment rates for antithrombotic and anticoagulation medications that had high compliance at baseline continued to show improvements, achieving almost 100% compliance in later years.[2,3] Several subsequent publications showed either continued improvements or sustained high levels of care compliance on key measures.[14–19] Early papers also highlighted disparities in care quality across different race/ethnic groups[20,21] and by sex,[22] while others focused on developing risk scores,[23,24] or demonstrating the association between improved care and better patient outcomes.[25–27] We highlight 2 important analyses that compared quality of care and patient outcomes among hospitals that either did or did not participate in the GWTG-Stroke

program. In the first study, data from the population-based REGARDS study (Reasons for Geographic and Racial Differences in Stroke) showed that ischemic stroke patients admitted to GWTG-Stroke hospitals received higher quality care than stroke patients who were admitted to nonparticipating hospitals.[28] In the second study, analysis showed that hospitals that joined the GWTG-Stroke program produced faster gains in patient-centered outcomes, including increased discharge to home and reductions in mortality, compared with similar hospitals that had not joined the program.[27] In the absence of data generated from randomized controlled trials, these findings provide the strongest available evidence for the impact of the GWTG-Stroke program on producing better quality of care and improved patient outcomes.

Contributions to the Development of Stroke Systems of Care

Over the last 20 years, GWTG-Stroke has become an integral part of the development of the nationwide stroke systems-of-care model, resulting in a complete redesign of the acute stroke care delivery system in the United States.[29–31] As mentioned earlier, while other organizations and programs,[11,32] including hospital certification,[33] have been critical to the development of a new systems-of-care model, the size and reach of the GWTG-Stroke program along with the data it provides have made a significant contribution to the effort. Notably, GWTG-Stroke reports that have addressed relevant system-level factors at the prehospital,[15,34,35] hospital,[36–39] posthospital, and regional levels[40–43] have been essential for motivating action and policy changes at the systems level, as well as at individual hospital, practice, and agency levels. Data from GWTG-Stroke document how changes in the stroke system of care have translated into greater access to endovascular therapy (EVT)[17] with reduced disparities across age, race, and sex.[44–46] The importance of hospital certification for EVT access and outcomes is illustrated by a recent GWTG-Stroke report that shows higher care quality and better outcomes for EVT patients treated at comprehensive or thrombectomy-capable stroke centers.[47]

Establishing a Community of Researchers Responsible for Broad Dissemination of Registry Findings

When the GWTG-Stroke program was first established, the AHA organized an oversight committee consisting of AHA staff, external stakeholders, and academic partners including stroke clinicians, health services researchers, and statisticians. The committee served to provide scientific guidance to the program, to develop project ideas, and to oversee the analysis, write-up, and dissemination of research findings. This multi-disciplinary committee has evolved into a community of like-minded researchers that has fostered a team-based approach characterized by high levels of productivity. Since the first analyses of GWTG-Stroke data were published in 2005, the GWTG-Stroke website currently lists 173 peer-reviewed publications with between 10 and 15 new papers added each year.[48]

Promotion of Hospital QI Efforts

A central goal of the GWTG-Stroke program is to improve the quality of care delivered to patients hospitalized with acute stroke. To achieve this, the program has taken a proactive

approach to engaging with hospitals to help them undertake QI initiatives, which has included alternative methods of information dissemination to front-line hospital staff (who do not always access the peer-reviewed literature). The GWTG-Stroke website[48] includes an array of educational tools, including webinars, workshops, and online mini-learning series where new registry findings are disseminated to hospital staff. The website also includes a range of resources designed to promote the implementation of QI programs, including specific data submission forms, clinical tools, and checklists. The success of this approach is illustrated by the Target Stroke QI campaigns,[49] which developed a range of toolkits specifically designed to help hospitals identify and solve barriers to the timely administration of IV tPA.[50,51] Details of the results of Target Stroke are reviewed further below.

Influence on Other Disease Registries and QI Programs

Of the 5 disease-specific QI registries overseen by the AHA, GWTG-Stroke is by far the largest in terms of both the number of participating hospitals (n=2635; Figure 1) and the total number of discharges recorded (≈9 million; Figure 2). The success of the GWTG-Stroke registry (along with the AHA's heart failure and coronary heart disease modules) provided the impetus to expand the AHA's disease-specific registries to include cardiac resuscitation and atrial fibrillation. More broadly, the success of the GWTG-Stroke program has been one of the drivers for the expansion of QI-based stroke registries across the globe,[52] including successful replications of the GWTG-Stroke registry in other countries, including Taiwan[53] and China.[54]

Figure 1. Geographic distribution of hospitals participating in Get With The Guidelines-Stroke between 2005 and 2023 (n=2635). **Figure 2**. Cumulative number of stroke discharges (in millions) captured in the Get With The Guidelines-Stroke program between 2005 and 2023.

WHY HAS THE GWTG-STROKE PROGRAM BEEN SO SUCCESSFUL? WHAT ARE THE LESSONS LEARNED?

Hospital Stroke Certification and the Need for Data

A key driver of the sustained growth of GWTG-Stroke was the establishment of hospital stroke certification programs by the Joint Commission,[33] other hospital certifying organizations,[55] and state-level programs. To obtain and maintain certification, hospitals need to submit performance data confirming that they are providing high-quality care (as indicated by meeting endorsed benchmarks on specific performance measures). For both primary and comprehensive stroke centers, the collection and submission of ongoing performance data (as curated by GWTG-Stroke) and participation in ongoing QI initiatives (as facilitated by GWTG-Stroke) became essential components of their work.[11,56] A critically important step in the development of this data-driven certification system was the establishment of a harmonized set of stroke performance measures,[57] which was endorsed by AHA, the Centers for Disease Control, and quality assurance

programs including the Joint Commission and the National Quality Forum.[4] A subset of these measures were subsequently selected by the Centers of Medicare Services as candidates for use in various hospital pay-for-reporting and pay-for performance programs,[58] although the final adoption of stroke-specific measures has been limited to date. In summary, the adoption by several key health care agencies, certifying bodies, and funders of a standardized set of stroke performance measures that required careful ongoing patient-level documentation by hospitals helped ensure the broad adoption of the GWTG-Stroke program, which had been specifically designed to facilitate the collection and reporting of these very measures. The key lesson learned is that it was vital for AHA to establish working partnerships with agencies and stakeholders involved in the promotion of high-quality acute stroke care as well as the redesign of stroke systems of care. Furthermore, ensuring that the hospital certification process relied on data-driven metrics provided further incentive for hospitals to participate in GWTG-Stroke.

Recognizing Hospital Success Through GWTG-Stroke Awards

From early on, the AHA recognized the importance of formally acknowledging the work of individual hospital teams by establishing a recognition program.[59] The GWTG-Stroke recognition program is structured around 3 tiers of award levels (bronze, silver, and gold), which identify hospitals that have achieved high levels of quality care over either a 3-month, 1-year, or 2-year time period. A high level of care is defined as achieving 85% compliance on 7 endorsed stroke performance measures. Hospital achievement awards are announced annually at a celebration at the International Stroke Conference, posted on the GWTG-Stroke website, and published in a special issue of the US News and World Report. Much of the success at the individual hospital level to improve care comes down to the hard work and commitment of a small number of team members. The public recognition of the work of hospital staff serves as an important motivator to sustain team efforts and affords them the opportunity to highlight their work to their own hospital leadership. Moreover, through advertising and marketing efforts, individual hospitals can use these awards to promote their work to local and regional communities. Thus, another key lesson learned is that recognizing the work of hospitals and hospital QI teams is an important component to sustaining the growth and continued high levels of hospital participation seen in the GWTG-Stroke registry.

Identifying Opportunities for QI

To address its central mission of improving the quality of acute stroke care, the GWTG-Stroke program has highlighted important gaps in care that have led to targeted QI projects being implemented across the registry. The best example of this is the highly successful Target Stroke campaign. While early data from GWTG-Stroke found a dramatic increase in the proportion of ischemic stroke patients treated with IV tPA,[2] faster time to treatment is strongly correlated with improved outcome, and only about a quarter of treated patients received the drug within 60 minutes of hospital arrival. Moreover, this time metric was static and had not meaningfully improved despite an increase in the overall treatment rates.[37] The first Target Stroke Quality Improvement Project had the goal of doubling the proportion of tPA-treated patients with a door-

to-needle time of <60 minutes to 50%.[60] The results of this first campaign were striking; the program met its goal by the end of the 3-year intervention period when the proportion of patients with a door-to-needle ≤60 minutes reached 53%.[61] Importantly, this reduction in time to treatment was associated with lower rates of symptomatic intracranial hemorrhage and in-hospital mortality and a greater likelihood of discharge home. The success of this first Target stroke project led to 2 additional campaigns to further reduce treatment delays.[62] The current Target Stroke III campaign seeks to achieve both shorter door-to-needle times for IV tPA and shorter door-to-device times for EVT.[49] The important lesson learned is the need for a QI program to identify the most important gaps in quality of care (in this case, the slow delivery of tPA) and to follow this up with an aggressive QI campaign designed to show rapid improvements in care. The effectiveness of the Target Stroke campaign was in large part due to the development and dissemination of specific QI tools and materials designed to speed up the delivery of TPA[48]; similar benefits are anticipated in the timeliness of EVT now that it has been included in the latest Target Stroke campaign.

Developing Young Investigators and Facilitating Data Access

The large number of people who have coauthored GWTG-Stroke papers, including many junior investigators, has been facilitated by having an open process to submit ideas for specific hypothesis-driven analyses, along with specific funding to support applications from early-career investigators.[63] More recently, online access to de-identified GWTG-Stroke data has been established through the AHA's Precision Medicine Platform.[64] The important lesson learned was the need for the program to actively promote the involvement of young investigators and to take specific steps to democratize data access. These steps have increased the reach and availability of the GWTG-Stroke data to interested researchers across the globe.

WHAT DOES THE FUTURE BRING? CHALLENGES AND OPPORTUNITIES

The Table summarizes several potential future threats and opportunities for the continued success of the GWTG-Stroke program.

Table. Summary of Potential Challenges and Opportunities for the GWTG-Stroke Program (Table view)

Potential challenges
1. Inability of hospitals to sustain abstractor-based data collection
Although most registries still rely on manual data collection and curation, it is well recognized that this requires substantial resources in terms of human capital, costs, and time.[65] The potential for registry data to be mined from electronic medical record (eMR) data is therefore very appealing and holds the potential to increase efficiency and timeliness of data access.[66] Improving the efficiency of data collection would help ensure hospitals continue to participate in clinical registries. However, considerable practical challenges exist in terms of incorporating eMR data into clinical registries, including system interoperability, data accuracy and completeness, lack of important clinical information (eg, contraindications), patient privacy, and data governance.[67,68] Thus, while increased integration of eMR data into Get With The Guidelines (GWTG)-Stroke would help lessen the burden of data abstraction, there remains a need for human operators to conduct

Potential challenges
manual data abstraction, curation, and monitoring.[68] However, the development of artificial intelligence (AI) tools that autocomplete data collection could change this situation.
2. Changes to privacy regulations and increased proprietary ownership of patient data
All participating GWTG-Stroke hospitals are required to comply with local regulatory and privacy guidelines and secure institutional review board approval. GWTG-Stroke is first and foremost a QI registry; because research is a secondary objective and occurs exclusively using de-identified data, federal regulatory policies assuring ethical and privacy standards (ie, the Common Rule and the Privacy Rule) are judged to not apply.[65,69] Most participating sites are therefore able to obtain either an exemption from human subjects review or a waiver of authorization such that individual patient consent is not required. However, future changes to the legal application of these policies to QI registries could threaten the current functioning of GWTG-Stroke. Several examples exist demonstrating how changes to the interpretation of existing regulatory policies have directly impacted disease registries.[69] A study from Canada illustrated how the introduction of requirements for individual patient consent had a dramatic negative effect on the representativeness and efficiency of a stroke registry.[70] It could also be argued that ongoing concerns about the ethical and regulatory standing of registries like GWTG-Stroke continue to stifle innovation. The linkage of registry data to external data sources (eg, claims) or the collection of patient-reported outcomes data following discharge are both complicated by the absence of individual patient consent. It is clear that the digital health care environment of today is very different from when GWTG-Stroke started 20 y ago. The potential to share content from large health databases with third-party technology companies, along with illicit security breaches of personal data, have raised concerns about the effectiveness of current privacy regulations.[71] Moreover, concepts of the quantified self[72] and patient ownership of their own health data[73] raise important but challenging questions related to data privacy, ownership, and patient consent. These and other changes to the current health data environment will continue to test the functioning and structure of disease registries in the future.
3. Exclusion of stroke from Centers of Medicare Services (CMS) payment reform and QI initiatives
Over the past decade, CMS has implemented several national payment reform and QI programs, including value-based purchasing and readmission reduction programs targeted at hospitals.[58] However, these 2 programs are currently limited to just 4 disease conditions (acute myocardial infarction, pneumonia, heart failure, and chronic obstructive pulmonary disease). Although stroke is included in the inpatient quality reporting program, this is limited to the public reporting of hospital-specific 30-d stroke mortality rates. The lack of emphasis on stroke in these CMS programs could be a potential risk to the GWTG-Stroke registry if it were to lead to hospitals dropping out of the registry because they do not see a benefit to tracking the quality of care for acute stroke patients.
Potential opportunities
1. Contributions from GWTG-Stroke data to the learning health system (LHS) framework
The concept behind the LHS is that health care systems can be redesigned so that they better use health information technology to optimize health care delivery.[74,75] Disease registries such as GWTG-Stroke can play a central role in the LHS concept because they can provide data that feeds a continuous learning cycle whereby “evidence informs practice” and “practice informs evidence.”[74] However, while there is clear overlap in the mission and functions of LHS and disease-specific QI-based registries, critical evaluation has found few tangible examples where GWTG-Stroke data are being applied to the LHS concept.[75] This gap represents an opportunity for GWTG-Stroke to align its data organization and processing so that it can be more readily used within the LHS framework. Case studies highlighting the application of GWTG-Stroke data by hospitals and health systems within the LHS framework would be valuable.
2. Automated data collection and real-time clinical decision support

Potential challenges
The recent advent of cloud storage and high-performance computing is revolutionizing data sciences and predictive analytics. These tools, along with generative AI tools powered by large language models, like GPT-4, promise to transform the way that health care is delivered. For example, GPT-4 outperformed medical-journal readers in diagnosing complex medical case challenges,[76] and custom large language models are now being deployed to use ambient listening to draft clinical notes and health portal message replies. These tools will also soon be able to suggest guideline-based care protocols to patients in real time, including personalized secondary stroke prevention based on pharmacogenetics. Other applications include AI-driven prediction models to improve post-discharge medication adherence or flag high-risk patients for enhanced monitoring to prevent readmission. The potential for AI-based tools to autocomplete data collection and thus greatly improve the efficiency of registries was mentioned earlier. Ultimately, how clinical registries leverage the power of AI so that they remain relevant but distinct from eMR data remains a key unknown.
3. Development of a patient self-management tool
Improving self-management skills in stroke survivors plays a critical role in improving secondary prevention of stroke (through medication adherence, risk factor control, and lifestyle change), while also promoting stroke recovery.[77] Because self-management requires ongoing training and engagement, eHealth-based technologies offer appealing, low–cost, and adaptable solutions to provide patient education, engagement, and risk factor control.[78,79] The AHA is currently pilot testing a mobile phone–based self-management tool to assist stroke patients (and caregivers) with their transition home following hospital discharge.[80] The tool includes a menu of curated educational materials, social support resources, symptom and risk factor tracking, medication management, and health self-assessments. Goal-setting options that target changes in lifestyle and risk factors are also provided. Importantly, future versions of the tool will offer the ability to incorporate patient-specific data from the GWTG-Stroke registry itself and potentially allow for the online collection of patient-reported outcomes.
4. Big data and opportunities for data linkage
Data generated by disease registries such as GWTG-Stroke have many of the cardinal features of big data, including large patient volumes, a broad variety of stroke subtypes, and the rapid availability of data.[81] However, a major limitation of GWTG-Stroke is the lack of follow-up data needed to identify readmissions, stroke recurrence, and deaths. Data linkage between registry data and claims data offers the opportunity to track patients posthospitalization.[69,82] Outcome events could also be tracked by linking registry and eMR data.[68] However, the ideal solution would be to develop unique patient identifiers that allow for linkage across hospitalizations and between hospital systems to provide a comprehensive picture of patient outcomes and utilization.
5. Generating population level surveillance data at national level
The United States lacks a timely and comprehensive surveillance system to track the burden of cardiac disease and stroke.[83] A recent study illustrated how GWTG-Stroke data can be repurposed as a surveillance resource by reweighting the data so it represents nationally representative data.[84] The ability of GWTG-Stroke registry data to provide more timely and nationally representative data on stroke hospitalization, including clinical care and outcomes, represents an important opportunity to better quantify the national stroke burden.
6. Addressing health disparities through social determinants of health (SDOH)
Registries play an important role in addressing gaps in care related to health care disparities[4,68] and in examining the role of SDOH. GWTG-Stroke publications have identified disparities in quality of care across different race/ethnic groups[20,21] and by sex,[22] while others have examined the effect of insurance status on disparities in both access to care and outcomes following stroke.[21,85,86] Analyses of GWTG-Stroke data have also shown evidence of reduced disparities over time in access to EVT treatment by age,[44] race,[45] and sex.[46] While GWTG-Stroke collects demographic data (age, sex, race/ethnicity, and insurance) that are often used as proxies for disadvantaged populations, it has not been able to collect more detailed SDOH data such

Potential challenges
as education, income, housing insecurity, sexual orientation, or perceived levels of discrimination. However, opportunities now exist to include these important variables in GWTG-Stroke. First, GWTG has recently included several new data fields that expand available patient-level information on SDOH, including gender identification and unmet social needs. Second, external data linkage offers an important opportunity to examine neighborhood-level SDOH data. For example, currently, efforts are ongoing to analyze census-derived SDOH data that have been linked to GWTG-Stroke, including education, employment, and poverty. Given the emphasis now being given to addressing SDOH[87] and structural racism,[88] opportunities to examine SDOH data will likely continue to expand in GWTG-Stroke and will hopefully lead to further reductions in disparities in stroke care and outcomes.
7. Embedded registry-based randomized clinical trials
There are ongoing challenges to conducting randomized clinical trials given the required infrastructure, administrative burden, poor efficiency, frequent delays, and excessive costs. Conducting clinical trials within established clinical registries like GWTG-Stroke offers the possibility of reducing many of these barriers.[89] The size of GWTG-Stroke, along with its robust data collection mechanisms and broad patient inclusion criteria, offer ideal starting conditions to implement pragmatic trials at scale with greater efficiency. Examples of trials and comparative effectiveness studies conducted within GWTG-Stroke include MaRISS, PROSPER, CHANGE AFib, and ARAMIS.[90]
8. Collection of cost data
There are at least 2 areas where the collection of cost data in GWTG-Stroke would make meaningful contributions. First, although largely undefined, costs to support the necessary data management resources required for individual hospitals to abstract and curate clinical data for disease registries are thought to be significant.[68] An important contribution of GWTG-Stroke would be to obtain detailed data on the operational costs of participating in the registry,[91] which could then be used to generate cost-effectiveness estimates of program participation.[65] Second, GWTG-Stroke could play an important role by collecting data on hospital costs. The United States has the highest average per-patient costs for stroke in the world,[92] but United States estimates of the cost of stroke vary dramatically, driven largely by differences in the populations studied and the cost-related methods utilized.[93,94] To date, the cost data available to GWTG-Stroke have been limited to Medicare fee-for-service claims, but as Medicare Advantage plans continue to expand, fee-for-service claims will represent an ever smaller proportion of admissions. Large representative hospital-based registries like GWTG-Stroke could provide data on hospital costs that could help fill the void of cost-of-care and cost-effectiveness studies in the United States.[95]

ARAMIS indicates Addressing Real-World Anticoagulant Management Issues in Stroke Registry; CHANGE AFib, Change Afib Pragmatic Stroke Prevention trial; GPT-4, Generative Pre-Trained Transformer- 4; MaRISS, Mild and Rapidly Improving Stroke Study; and PROSPER, Patient-Centered Research Into Outcomes Stroke Patients Prefer and Effectiveness Research.

CONCLUSIONS

The GWTG-Stroke registry represents a major success story given its impact on stroke care in the United States. The participation of so many US hospitals over the past 20 years has resulted in a large, nationally representative database that has demonstrated sustained increases in both the quality of care and patient outcomes over time. GWTG-Stroke has played a central role in the redesign of stroke systems of care including hospital certification, performance measure development, and pay-for-reporting programs. Several features of GWTG-Stroke can serve as models for other QI-based registries, including the development of targeted QI interventions, the

hospital awards program, the broad dissemination of research findings, and the promotion of junior investigators. However, the technological and regulatory environments affecting health care data in the United States are ever-changing, and the registry needs to continue to be vigilant for both future opportunities and challenges to its position as one of the most important disease registries in the United States. This includes the willingness to change its organization, function, and structure as external forces dictate.

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