

NC HIEA February 2023 Update | NC HIEA

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Anna Bess Brown, Executive Director of the Justus-Warren Heart Disease and Stroke Prevention Task Force

Stroke Registry Dashboard, a New Public Health Tool Launches for NC HealthConnex

On February 15, 2023, the N.C. Health Information Exchange Authority launched the North Carolina Stroke Registry, a population health tool that supports the N.C. Division of Public Health (DPH). The dashboard leverages demographic and clinical data on stroke patients that is received by NC HealthConnex to improve the stroke care continuum.

In 2021, DPH and the N.C. Stroke Advisory

Council led the efforts to secure a grant from the Paul Coverdell National Acute Stroke Program that funded the development of the Registry. Anna Bess Brown, Executive Director of the <u>Justus-Warren Heart Disease and Stroke Prevention Task Force</u> and the Stroke Advisory Council said she is excited to see those efforts paying off.

"Having this registry is providing us with data and with opportunity to provide state-of-the-art care no matter where you live and to explore areas of need in our state and to identify gaps in care so that we can address these issues through the training of providers, providing resources for hospitals, and so that we can seek funding to improve our statewide system of care," said Brown.

The N.C. Stroke Advisory Council, the N.C. Department of Health and Human Services, and members of the health care community were present to view the demonstration of the Stroke Registry dashboard on the campus of the NC HIEA's technical partner, SAS.

The registry uses existing data for its dashboards from more than 9,000 facilities connected to NC HealthConnex at this time. The dashboard gives a visualization of the prevalence of stroke by county and by zip code, tracks analysis on comorbidities, and identifies trends based on demographics such as race and age. Data regarding stroke patients from emergency medical services connected to the HIE is planned to be included in a future enhancement in cooperation with the Office of Emergency Medical Services.

The Stroke Registry project aims to improve the system of care for stroke patients in North Carolina; identify areas in the stroke care continuum where interventions may be needed, whether that involves stroke prevention or post-stroke care measures; and address disparities in care.

"Stroke is the fourth leading cause of death in our state, and in the U.S., it's the fifth, so we really do have a problem with stroke," said Brown. "For many people, once it hits their family, they become aware of the problems with it. A lot of people can't go back to work, or they're really limited in their speech or in their mobility."

A <u>study led by Duke University</u> recently revealed that the algorithms used to identify stroke risks perform worse for Black individuals. Better data collection could help improve that disparity.

There is also a need for identifying stroke risks and outcomes in communities where there may not be larger hospitals or health systems. Brown explained that although many hospitals in North Carolina are stroke-certified, the stroke registry will provide information on stroke in all areas of the state, including those with fewer resources.

"We're not just capturing those hospitals that are very well-resourced, but everybody across the state, so we're getting a more complete picture of stroke in our state. We'll get a certain level of data from the population level from the HIE; there's no other device that can do that," said Brown.



The NC HIEA presents a demonstration of the NC Stroke Registry dashboard at SAS.

The data in the dashboard is aggregated at the population level, meaning that it is not possible to identify specific patients by using the dashboard. Data is suppressed for small populations where identification is more possible. The Stroke Registry dashboard is currently only accessible by a handful of state employees in the Division of Public Health who have both an NCID and authorization to access the dashboards.

Teams at both the NC HIEA and SAS are working on new developments for the project and are already gathering requirements for new phases. Future versions of the registry may include granting access to the aggregated data to health care providers so they can work with DPH to improve the standard of care.

Brown said the overall goal is to ensure that all North Carolinians receive the best standard of care, regardless of race, ethnicity or geographic distance, "We want you to be taken care of in the best way possible anywhere you have a stroke in NC. If you live an hour away from a hospital, that is significant; and if that hospital closes or is so small that they have to transfer you to another hospital, that takes time, and time is brain."