The Kentucky Appalachian Stroke Registry (KApSR)

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Background: The population of rural Kentucky and West Virginia has a disproportionately high incidence of stroke and stroke risk factors. The Kentucky Appalachian Stroke Registry (KApSR) is a novel registry of stroke patients developed to collect demographic and clinical data in real time from these patients' electronic health records. *Objective:* We describe the development of this novel registry and test it for ability to provide the information necessary to identify care gaps and direct clinical management. *Methods:* The KApSR was developed as described in this article. To assess utility in patient care, we developed a "Diabetes Quality Assurance Dashboard" by cross-referencing patients in the registry with a diagnosis of ischemic cerebrovascular disease with patients that were tested for hemoglobin A1c (HbA1c) levels, patients with HbA1c levels diagnostic for diabetes mellitus (DM), and patients with an elevated HbA1c that were formally diagnosed with DM. *Results:* For the 1008 patients treated for ischemic cerebrovascular disease in the year studied, 859 (85%) had their HbA1c tested. Of those, 281 had levels of 6.5 or greater, although only 261 (93%) were discharged with a formal diagnosis of DM. *Conclusions:* The KApSR has practical value as a tool to assess a large population of patients quickly for care quality and for research purposes. **Key Words:** Stroke—registries—public health—epidemiology—health care database—diabetes.

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Introduction

People living in rural areas such as Appalachian Kentucky suffer a disproportionate burden of negative health disparities. Various behavioral, health, and socioeconomic factors increase disability risk among such groups. Chronic health conditions that are "disability risk factors" include heart disease and stroke, diabetes, peripheral artery disease, chronic obstructive pulmonary disease, cancer, depression, and cognitive impairment.[1] Heart disease and stroke, the two strongest disability risk factors, are increased in incidence in rural Appalachia compared with non-Appalachian regions.[2]

According to the United Health Foundation, Kentucky ranks 43rd among all states for health indicators such as diabetes (38th), high blood pressure (47th), obesity (46th), poor physical health days (49th), high

cholesterol (49th), heart disease (48th), high school graduates (32nd), median income (45th), and preventable hospital readmissions (50th). Of 386 persistent poverty counties in the United States, 43 are in Kentucky, with the vast majority of these located in the rural Appalachian regions of Kentucky.[3] Appalachian regions have been associated with low socioeconomic status, which has been shown to be associated with worse stroke severity. Similarly, a positive correlation exists between stroke severity and years living in the stroke belt. Higher economic status is associated with longer life expectancy and longer disability-free life expectancy.[4-6]

Smoking, hypertension, diabetes, and obesity are known risk factors for stroke, and are increased in prevalence in Kentucky compared with most other states.[7] In 2014, Kentucky ranked 47th among the states in stroke incidence in the adult population.[8] The highest death rates for stroke occur in the southeastern United States (the "stroke belt"), and 26 counties in Appalachian Kentucky have some of the highest stroke incidence rates in the stroke belt.[9]

The University of Kentucky Stroke Care Network, which includes hospitals in the Appalachian region, was created in 2008 in accordance with American Heart/American Stroke Association recommendations for the organization of stroke systems of care. A variety of process metrics were employed to assess the impact of the network, including improvements in quality of care (i.e., length of stay, mortality, intravenous thrombolytic administration, laboratory result times, stroke measures). From 2008 to 2016 the network grew to include 28 hospitals in 2 states (Kentucky and West Virginia), 2 Comprehensive Stroke Centers, 6 Primary Stroke Centers, and 1 Acute Stroke Ready Hospital. Norton Healthcare, a not-for-profit system based in Louisville, Kentucky, became a co-sponsor of the network in 2011, at which time the network strategy was reinvigorated. At the heart of the network strategy is the formation of a network-wide stroke care registry.

Better understanding of stroke care rendered, sometimes population based, is often accomplished through disease-specific registries.[10-12] Stroke registries containing comprehensive data help to understand how demographics, comorbid conditions, and other factors interact to influence health, access to care, and response to therapies. In addition, there is a need for enhanced approaches to detecting potential safety issues with drugs and devices for stroke patients.

Historically, stroke registries have been dependent on chart abstraction. There are many examples of generalizable stroke care knowledge that have been gleaned from these stroke registries. Such registries typically utilize a single database, require skilled nurse or technicians to abstract data, and are prone to errors because of judgment at the abstraction level. A serious limitation of abstraction registries is that they are time-consuming and expensive to go back in and add data elements after abstraction has begun. Abstraction registries therefore hold limited data, hold data that are several years old, are relatively inflexible to add new elements, and as a result are slow to drive change.

In today's evolving health care environment, registries not only need to provide generalizable data for research, but also should provide quick data feedback to influence care at the local level. We need registries that report recent or real-time data, are intrinsically accurate, are flexible for adding new elements, and hold comprehensive data. Today's era of the electronic health record (EHR) should allow for development of large stroke registries based on data capture and sharing independent of chart abstraction and therefore, one would hope, are more cost-effective.

Recent studies suggest that to drive substantial gains in quality and efficiency, simply adopting electronic health records is insufficient to produce higher quality care or better clinical outcomes.[1314] Although electronic tools are being used, their integration with clinical care and their ability to support quality in real time may be insufficient to improve overall quality of care or outcomes for stroke. There remains the need to establish and test a stroke registry developed with EHR data that can be used to support clinical decision making and will drive better care.

The purpose of this study is to establish the utility of a novel stroke registry making use of EHR data. Specifically, we describe the development of this novel registry and test it for ability to provide the information necessary to identify care gaps and support clinical decision making. Another goal is to establish that the registry is comprehensive—that the clinical and research questions are only limited to the extent of searchable identifiable data points.

Methods

Development of the Kentucky Appalachian Stroke Registry

Data are provided through the University of Kentucky Center for Clinical Translational Sciences Enterprise Data Trust. This trust contains clinical data from each of the UK HealthCare electronic systems, which have been integrated into a data warehouse. The UK HealthCare clinical data warehouse primarily captures the inpatient population of all patients seen at the University of Kentucky and at the time of this writing contains data from more than 554,300 individuals. For the purposes of the stroke registry, data starting in 2010 to the present are being utilized. This data warehouse contains the following data elements: (1) demographics (e.g., age at time of hospitalization, gender, marital status, race); (2) provider level detail (services provided); (3) medical diagnoses (International Classification of Diseases, Ninth Revision,