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...
Appalachian regions have been 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.13-14 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,
THE KENTUCKY APPALACHIAN STROKE REGISTRY

[ICD-9 and Tenth Revision [ICD-10 codes]; (4) medical procedures (inpatient facility and technical procedures; Current Procedural Terminology (CPT) codes); (5) laboratory tests and results (e.g., chemistry, coagulation, hematology, urinalysis); (6) medications received; (7) visit details (length of stay, financial classification, service unit, weekend admission); and (8) vital signs (e.g., height, weight, body mass index, direct arterial blood pressure, noninvasive blood pressure, heart rate, pulse oximetry, respiratory rate, temperature, death status, tobacco status).

Data related to stroke are extracted from the Enterprise Data Trust and stored on an Oracle Database 12c Enterprise Edition Release 12.1.0.1.0—64-bit production server. Oracle Structured Query Language (SQL) Developer 3.2.20.10 was used to create the registry. Data filters were developed using ICD-9 codes and ICD-10 codes (Table 1). The data are stored utilizing third-level normalization based on the type of data to develop the overall stroke categories (see Fig 1). The registry design provides a dynamic infrastructure that incorporates changes in patient data within the health care system, usually within 24 hours of EHR entry.

Validation Process

The system configuration itself provides substantial safeguards for validation of data at the level of the electronic medical record and the data warehouse. This includes data type and range, and constraint validation of input, of diagnostic codes, and of physical-level data. Many of these are “automatic” validations such as drop-down menus with limited input selections (such as for the National Institutes of Health Stroke Scale) at the level of patient care.

During the development phase, the data were continually checked against current University of Kentucky Stroke Program data reports to validate the data. The program’s reports were based on ICD diagnosis and procedure codes and manual chart abstraction. In addition, data from randomly selected medical files were compared against the database.

For each new data definition, code and cross-reference validation exercises occurred. This helped to ensure accuracy of datasets created from our definitions. It was recognized that there would be a need for validation of each new data definition as the registry moves forward.

Datasets were compared for agreement with the electronic medical records of patients through hand abstraction as a final, “gold-standard” validation procedure. This occurred for hundreds of records. In one instance, where information in the dataset showed differences from the medical records, a key underlying system error was discovered that was causing inaccurate translation of computer codes for lipid profiles. Correcting this error benefited the entire data warehouse system.

Development of Clinically Useful Tools: The Diabetes Quality Assurance Dashboard

To test the ability of this registry to influence care, we developed a diabetes mellitus (DM)–related dashboard for individuals with ischemic cerebrovascular disease (ICVD). The DM dashboard was developed with a 3-graph format that follows a clinical decision making sequence.

The goal of the dashboard was to investigate how well DM is recognized in our ICVD population. This would require us to define the population to be studied, taking a “data snapshot” to create the dataset for study. This would be followed by creation of data definitions using computer code to extract and categorize patient data from the “snapshot” database into distinct groups, such as those who have had an HbA1c test, and those who were diabetic and also left the facility with the diagnosis of DM. We anticipated high rates of HbA1c testing in our ICVD dataset, and few if any instances of patients who are diabetic leaving without the diagnosis.

Using ICD-9 codes for ICVD (Table 1) the population of interest was developed. A series of SQL statements were developed that included the laboratory code (HbA1c), the principal diagnosis codes, the date range, the diagnosis codes for DM, and the HbA1c threshold value of 6.5 (Table 2). This allowed 2 charts to be developed: 1 chart shows the number of individuals with an ICVD that had the HbA1c test performed, and 1 chart shows the number of individuals who had the HbA1c test and had a value greater than or equal to 6.5%, which is diagnostic of DM. Another series of SQL statements was used to develop a third chart that shows the number of individuals who had an HbA1c of 6.5 or higher who were given a diagnosis of DM.

Results

Layout of Kentucky Appalachian Stroke Registry

The registry is developed in a step-down fashion in which we have an overall searchable population of all individuals with a diagnosis of cerebrovascular disease (CVD)—see Figure 1 and nested subgroups. From the CVD dataset 2 groups were nested: 1 containing all individuals with a diagnosis of a hemorrhagic CVD (HCVD), and 1 with ICVD. From the ICVD population 2 subgroups were nested: 1 for elective ICVD and 1 for acute ischemic cerebrovascular disease (AICVD). AICVD was then finally divided into 2 populations: acute ischemic stroke and transient ischemic attack. All of the groups mentioned are now predefined searchable populations within our stroke registry. Additional populations can be added to the overall scheme as needed. For example, the HCVD dataset has been further subdivided into subarachnoid hemorrhage, unruptured aneurysm, and intracerebral hemorrhage searchable datasets.
<table>
<thead>
<tr>
<th>Category of stroke</th>
<th>ICD - 9 codes</th>
<th>ICD - 10 codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall cerebrovascular disease</td>
<td>430, 431, 437.3, 433.00, 433.01, 433.10, 433.11, 433.20, 433.21, 433.30, 433.31, 433.80, 433.81, 433.90, 433.91, 434, 434.10, 434.11, 434.90, 434.91, 435, 435.20, 435.21, 435.30, 435.31, 435.80, 435.81, 435.90, 435.91, 436, 436.10, 436.11, 436.20, 436.21, 437, 437.10, 437.11</td>
<td>I60 I61 I63 G45.8 G45.9 I67.1</td>
</tr>
<tr>
<td>Hemorrhagic CVD</td>
<td>430 431 437.3</td>
<td>I60.00 I60.01 I60.02 I60.10 I60.11 I60.12 I60.2 I60.30 I60.31 I60.32 I60.4 I60.50 I60.51 I60.52 I60.6 I60.7 I60.8 I60.9 I61.0 I61.1 I61.2 I61.3 I61.4 I61.5 I61.6 I61.7 I61.8 I61.9 I67.1</td>
</tr>
<tr>
<td>Subarachnoid hemorrhage</td>
<td>430</td>
<td>I60.00 I60.01 I60.02 I60.10 I60.11 I60.12 I60.2 I60.30 I60.31 I60.32 I60.4 I60.50 I60.51 I60.52 I60.6 I60.7 I60.8 I60.9</td>
</tr>
<tr>
<td>Intracerebral hemorrhage</td>
<td>431</td>
<td>I61.0 I61.1 I61.2 I61.3 I61.4 I61.5 I61.6 I61.8 I61.9</td>
</tr>
<tr>
<td>Ischemic CVD</td>
<td>433 433.01 433.10 433.11 433.2 433.21 433.3 433.31 433.8 433.81 433.9 433.91</td>
<td>I63.00 I63.01 I63.02 I63.03 I63.04 I63.05 I63.06 I63.07 I63.08 I63.09 I63.10 I63.11 I63.12 I63.13 I63.14 I63.15 I63.16 I63.17 I63.18 I63.19 I63.20 I63.21 I63.22 I63.23 I63.24 I63.25 I63.26 I63.27 I63.28 I63.29 I63.30 I63.31 I63.32 I63.33 I63.34 I63.35 I63.36 I63.37 I63.38 I63.39 I63.40 I63.41 I63.42 I63.43 I63.44 I63.45 I63.46 I63.47 I63.48 I63.49 I63.50 I63.51 I63.52 I63.53 I63.54 I63.55 I63.56 I63.57 I63.58 I63.59 I63.60 I63.61 I63.62 I63.63 I63.64 I63.65 I63.66 I63.67 I63.68 I63.69 I63.70 I63.71 I63.72 I63.73 I63.74 I63.75 I63.76 I63.77 I63.78 I63.79 I63.80 I63.81 I63.82 I63.83 I63.84 I63.85 I63.86 I63.87 I63.88 I63.89 I63.90 I63.91 I63.92 I63.93 I63.94 I63.95 I63.96 I63.97 I63.98 I63.99</td>
</tr>
<tr>
<td>Acute ischemic stroke</td>
<td>433 433.01 433.10 433.11 433.2 433.21 433.3 433.31 433.8 433.81 433.9 433.91</td>
<td>I63.00 I63.01 I63.02 I63.03 I63.04 I63.05 I63.06 I63.07 I63.08 I63.09 I63.10 I63.11 I63.12 I63.13 I63.14 I63.15 I63.16 I63.17 I63.18 I63.19 I63.20 I63.21 I63.22 I63.23 I63.24 I63.25 I63.26 I63.27 I63.28 I63.29 I63.30 I63.31 I63.32 I63.33 I63.34 I63.35 I63.36 I63.37 I63.38 I63.39 I63.40 I63.41 I63.42 I63.43 I63.44 I63.45 I63.46 I63.47 I63.48 I63.49 I63.50 I63.51 I63.52 I63.53 I63.54 I63.55 I63.56 I63.57 I63.58 I63.59 I63.60 I63.61 I63.62 I63.63 I63.64 I63.65 I63.66 I63.67 I63.68 I63.69 I63.70 I63.71 I63.72 I63.73 I63.74 I63.75 I63.76 I63.77 I63.78 I63.79 I63.80 I63.81 I63.82 I63.83 I63.84 I63.85 I63.86 I63.87 I63.88 I63.89 I63.90 I63.91 I63.92 I63.93 I63.94 I63.95 I63.96 I63.97 I63.98 I63.99</td>
</tr>
<tr>
<td>Transient ischemic attack</td>
<td>435 435.1 435.2 435.3 435.8 435.9</td>
<td>G45.8 G45.9 with Admission Type Code not = elective</td>
</tr>
</tbody>
</table>

Abbreviations: CVD, cerebrovascular disease; ICD-9, International Classification of Diseases, Ninth Revision; ICD-10, International Classification of Diseases, Tenth Revision.
Patient Population for the Kentucky Appalachian Stroke Registry

From 2010 to 2015 there were 8054 cases of CVD seen at the University Hospital (Table 3). Of these 8054 cases, 1780 are HCVD; 6274 are ICVD; 5666 are AICVD; 1118 are transient ischemic attacks; and 4548 are acute ischemic stroke.

Diabetes Quality Assurance Dashboard Prototype

The results of the DM dashboard (Fig 2) indicate that 859 of 1008 (85%) individuals who had a diagnosis of ICVD in fiscal year 2014 had a HbA1c test conducted (Fig 2, A). Of those who had an HbA1c test, 281(33%) had a level greater than or equal to 6.5 (Fig 2, B). Of those who had an HbA1c greater than or equal to 6.5%, 261 (93%) received a diagnosis of DM (Fig 2, C).

Registry Use for Research

The Kentucky Appalachian Stroke Registry has been configured so that the data can be filtered to provide information without personal identifiers to ask research questions from a large dataset. This function of the registry is linked with the University of Kentucky’s Center for Clinical and Translational Science.

Individual investigators can make use of the data through a protected online electronic request form. The investigator can specify details of the data to be extracted through the form.

Conclusions and Discussion

Physicians ultimately want to be able to effectively and efficiently provide high quality care to their patients. This is emphasized in the medical community with outcome-based reimbursement plans posited for the future, such as the Physician Quality Reporting System from the Centers for Medicare and Medicaid. Several recent studies have suggested that to drive substantial gains in quality and efficiency, simply adopting electronic health records is likely to be insufficient to provide higher quality of care.\textsuperscript{1314} Although electronic tools are being used, their ability to support quality in real time is insufficient to improve overall quality of care or outcomes for stroke. One of these studies suggests that new policies and methodologies are needed for using large datasets from EHRs before such work will lead to improvements in care. Our study represents a new methodology.

The KApSR is not a traditional registry but is a new data management system that through metadata-based definitions allows extraction of data into relevant snapshot datasets for further action. Metadata is defined as the data providing information about 1 or more aspects of the data; it is used to summarize basic information about data that can make tracking and working with specific data easier.

The novel metadata-assisted registry that is represented in the KApSR is very flexible and allows for infinite database “snapshots” for customized study to be developed. The registry is reliant on programming and code. It is simple to go back and add or define data elements (variables) at any point. Because the data warehouse is updated every 24 hours, the KApSR can provide almost real-time information that can be used in clinical decision making.

The KApSR in no way aims to supplant existing registries (i.e., the Physician Quality Reporting System (PQRS) outcome measure registry as mentioned previously). On the contrary, it represents a tool that can act synergistically to help our providers systematically analyze patient care and identify areas of treatment gaps, as in our diabetes example. Once identified, large-scale efforts can be enacted to address these shortcomings with the goal of ultimately improving patient outcomes. We hope to validate this logic in the future by systematically examining variables before and after intervention.

At inception the registry was able to provide retrospective data for several years allowing for research questions to be developed and examined from a large dataset. Data filters based on existing codes allow for customized searching. We have created what we think are useful, reproducible data filters (Fig 1) and emphasize that one could easily create additional filters based on codes for virtually any subset of the cerebrovascular population.

Validation of our registry data is a multifaceted process, with checks at every layer of the system. It seems that the most important and time-consuming part is that of
**Table 2.** Structured Query Language (SQL) statements used to develop the diabetes dashboard

<table>
<thead>
<tr>
<th>SQL statement used to develop the overall HbA1c test chart and the number of individuals with a ≥6.5 chart.</th>
<th>SQL statements used to develop the number of individuals with a high HbA1c that then were given a diagnosis of diabetes mellitus.</th>
</tr>
</thead>
</table>

Abbreviation: HbA1c, hemoglobin A1c.
code and cross-reference validation of each new data definition. However, this is worthwhile because validating each data definition upfront ensures that the intended data are being extracted each time.

Our novel registry has several advantages to chart abstraction-dependent registries. Our method is limited only by data points available electronically, and allows new data points to be added and retrospectively studied at any time. Our method allows for unique searchable snapshot datasets to be created for study. The registry can populate customized quality of care reports that can impact care delivery. The method developed to create this registry is also transferable to other disease states such as heart disease and cancer.

The prototype dashboard for DM provided us with surprising data about stroke and diabetes care gaps. First, we were surprised that only 85% of ICVD patients were tested for DM by HbA1c. This may identify a gap for intervention. A second care gap identified is that of those patients who had DM by HbA1c criteria, 7% remained undiagnosed at discharge and were presumably untreated afterward. These findings have been brought to the attention of the stroke care team, and interventions are being considered as of this writing.

Once the template for a particular dashboard has been developed (in this case the DM dashboard), the dashboard can be generated automatically as needed. We will re-analyze the diabetes dashboard after intervention.

Next steps are to continue to add data from network hospitals and to develop hundreds of additional data definitions for variables. These steps will strengthen the breadth and quality of our stroke network data. We will continue to prototype and test clinical tools, such as dashboards and gap analysis applications, striving to find areas for care improvement that will improve outcomes in our patient population.

### Table 3. Overview of demographics and types of cerebrovascular disease in the Kentucky Appalachian Stroke Registry

<table>
<thead>
<tr>
<th>Year</th>
<th>Patients</th>
<th>Males</th>
<th>Females</th>
<th>CVD</th>
<th>HCVD</th>
<th>ICVD</th>
<th>AICVD</th>
<th>TIA</th>
<th>AIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>1377</td>
<td>673</td>
<td>704</td>
<td>1537</td>
<td>339</td>
<td>1198</td>
<td>1061</td>
<td>172</td>
<td>889</td>
</tr>
<tr>
<td>2014</td>
<td>1401</td>
<td>719</td>
<td>682</td>
<td>1552</td>
<td>380</td>
<td>1172</td>
<td>1067</td>
<td>188</td>
<td>879</td>
</tr>
<tr>
<td>2013</td>
<td>1230</td>
<td>603</td>
<td>627</td>
<td>1357</td>
<td>326</td>
<td>1031</td>
<td>934</td>
<td>133</td>
<td>801</td>
</tr>
<tr>
<td>2012</td>
<td>1191</td>
<td>594</td>
<td>597</td>
<td>1323</td>
<td>287</td>
<td>1036</td>
<td>927</td>
<td>213</td>
<td>714</td>
</tr>
<tr>
<td>2011</td>
<td>1146</td>
<td>563</td>
<td>583</td>
<td>1230</td>
<td>210</td>
<td>1020</td>
<td>933</td>
<td>210</td>
<td>723</td>
</tr>
<tr>
<td>2010</td>
<td>1004</td>
<td>491</td>
<td>513</td>
<td>1055</td>
<td>238</td>
<td>817</td>
<td>744</td>
<td>202</td>
<td>542</td>
</tr>
<tr>
<td>Mean</td>
<td>1225</td>
<td>607</td>
<td>618</td>
<td>1342</td>
<td>297</td>
<td>1046</td>
<td>944</td>
<td>186</td>
<td>758</td>
</tr>
<tr>
<td>SD</td>
<td>148.6</td>
<td>80.6</td>
<td>69.7</td>
<td>188.5</td>
<td>64.25</td>
<td>135.9</td>
<td>117.8</td>
<td>30.2</td>
<td>129.2</td>
</tr>
<tr>
<td>Total</td>
<td>7349</td>
<td>3643</td>
<td>3706</td>
<td>8054</td>
<td>1780</td>
<td>6274</td>
<td>5446</td>
<td>1118</td>
<td>4548</td>
</tr>
</tbody>
</table>

Abbreviations: AICVD, acute ischemic cerebrovascular disease; AIS, acute ischemic stroke; HCVD, hemorrhagic cerebrovascular disease; ICVD, ischemic cerebrovascular disease; SD, standard deviation; TIA, transient ischemic attack.

**Figure 2.** Diabetes gap analysis: (A) shows how many individuals who had a diagnosis of ischemic cerebrovascular disease were also tested for diabetes using a HbA1c test; (B) shows how many of those patients that were tested had a value consistent with diabetes. Of the patients with diabetes mellitus by HbA1c criteria, the number of patients given this diagnosis by discharge is demonstrated in (C). Abbreviations: DM, diabetes mellitus; HbA1c, hemoglobin A1c; ICVD, ischemic cerebrovascular disease.
References