IOWA STROKE REGISTRY
National Initiatives for a Stroke Registry

• 2001: AHA/ASA Get With The Guidelines (GWTG) Stroke Pilot was launched. A web-based program created to help hospitals improve the quality of care they provide to stroke patients.
• 2002: The Federal Legislation known as Stroke Treatment and Ongoing Prevention (STOP) Act was filed.
• 2003: Joint Commission on Accreditation of Healthcare Organizations (JCAHO) an independent, not-for-profit organization that evaluates and accredits programs and healthcare organization launched their Primary Stroke Certification.
• 2007: CDC’s Paul Coverdell National Stroke Registry, Joint Commission’s Primary Stroke Center Certification Program and AHA/ASA GWTG harmonized all three programs and reached a consensus for one set of performances measures.
• 2009: CDC funded IDPH for Stroke Registry Design Project
What is a Patient Registry?

A patient registry:
• Is an organized system that uses observational study methods to collect uniform data (clinical and other)
• Evaluates specified outcomes for a population defined by a particular disease, condition, or exposure, and that
• Serves a predetermined scientific, clinical, or policy purpose

Key Characteristics of Registries

- Data are collected in a naturalistic manner
- Registry is designed to fulfill specific purposes, and these purposes are defined in advance of collecting and analyzing the data
- Registry captures data elements with specific and consistent data definitions
- Data are collected in a uniform manner for every patient.
- Data collected derive from and are reflective of the clinical status of the patient (by history, examination, laboratory test, or patient reported)
- At least one element of registry data collection is active, meaning that some data are collected specifically for the purpose of the registry
The Mission of the Paul Coverdell National Acute Stroke Registry

The **mission** of the PCNASR is—

- Measure, track, and improve the quality of care and access to care for stroke patients from onset of stroke symptoms through rehabilitation and recovery.
- Decrease rate of premature death and disability from stroke.
- Eliminate disparities in care.
- Support development of stroke systems of care that emphasize quality of care.
- Improve access to rehabilitation and opportunities for recovery after stroke.
- Increase the workforce capacity and scientific knowledge of stroke care within stroke systems of care.

The **near-term goals** of the PCNASR are to—

- Encourage the development of statewide systems of care for stroke patients through coordination with emergency medical services and collaboration among statewide partners.
- Communicate with major stakeholders in stroke care to ensure ongoing improvement in the quality of that care.

The **long-term goal** of this program

- To ensure that all Americans receive the highest quality of acute stroke care currently available and to reduce the number of untimely deaths attributable to stroke, prevent stroke-related disability, and prevent stroke patients from suffering recurrent strokes.
In 2001, Congress charged CDC with implementing state-based registries that measure and track acute stroke care and to use data from the registries in efforts to improve the quality of that care.

Congress further directed that this project be named the Paul Coverdell National Acute Stroke Registry, after the late U.S. Senator Paul Coverdell of Georgia, who suffered a fatal stroke in 2000 while serving in Congress.

"Wave I" projects, funded in 2001, were located in Georgia, Massachusetts, Michigan, and Ohio.

"Wave II" projects, funded in 2002, were located in California, Illinois, North Carolina, and Oregon.

These prototype projects gathered data concerning each step of emergency and hospital care for stroke patients, from emergency response to the patients' eventual discharge from a hospital. At the end of the 3-year pilot period, the results showed that large gaps existed between generally recommended guidelines for treating stroke patients and actual hospital practices. Intensive quality improvement efforts are needed to close those gaps.
PCNASR History

• In June 2004, CDC provided funds to the state health departments of Georgia, Illinois, Massachusetts, and North Carolina to establish statewide Coverdell stroke registries for acute care hospitals in their states.
  – The purpose of these registries was to develop and implement systems for collecting data on acute stroke care provided to patients, analyzing the collected data, and using the results of those analyses to guide quality improvement interventions at the hospital level through partnerships with hospital doctors, stroke-care teams, and administrators. All acute care hospitals serving the general population in participating states were eligible for the program.

• In July 2007, CDC expanded funding to six state health departments in Georgia, Massachusetts, Michigan, Minnesota, Ohio, and North Carolina for the Paul Coverdell National Acute Stroke Registry for a new 5-year funding period
2012-2015 Coverdell States

- Arkansas: In-hospital care and EMS
- California: In-hospital care and EMS
- Georgia: In-hospital care and EMS
- Iowa: In-hospital care and EMS
- Massachusetts: In-hospital care, EMS, and Post-hospital Transition of Care
- Michigan: In-hospital care and Post-hospital Transition of Care
- Minnesota: In-hospital care and EMS
- New York: In-hospital care
- North Carolina: In-hospital care and EMS
- Ohio: In-hospital care and Post-hospital Transition of Care
- Wisconsin: In-hospital care and EMS
Data Collected in PCNASR

• Demographic Data
• Pre-hospital and EMS Data
• Hospital Arrival and Admission Data
• Imaging
• Signs & Symptom Onset
• Thrombolytic treatment
• Medical History
• In-hospital Treatment
• In-hospital Complications
• Discharge Data
Consensus Group for Stroke Performance Measures

The Joint Commission – Primary Stroke Centers

AHA/ASA Get With The Guidelines - Stroke

Paul Coverdell
National Acute Stroke Registry
PCNASR Benefits

• Provides organized QI assistance to hospitals
• Creates environment for sharing ideas and discussing barriers between hospitals and states
• Fosters collaboration between hospitals and states
• Provides expertise for data collection
Iowa Stroke Registry Goals

- To implement standard definitions and protocols for inclusion in the stroke registry
- To provide data at the point of care
- To gather data in a systematic manner
- To maintain quality data for retrieval
- To analyze data to meet public health, stroke system quality improvement and research needs
- To disseminate information to the public, state officials, committees and health care providers.
Data Sources For Iowa Stroke Registry

• Death certificates from stroke*
• EMS data*
• Hospital Discharge data*
• *State Stroke Registry*
• *Stroke transfer data*
• Stroke rehab and follow-up

* Existing data
Data Capture by EMS and Hospital Providers

Point of Care Data and Transfer

Patient

EMS

Stroke Diagnosis And Transfer Hospital

EMS

Primary Stroke Center

EMS

Stroke Treatment Center

EMS

Thrombolytic Therapy or Hemorrhagic Stroke
Iowa Stroke Registry

• Data dictionary – defines data elements
  – Paul Coverdell Stroke Registry (template)
  – Stroke measures – Joint Commission, GWTG, PCNASR, CMS, AHRQ

• Design
  – Centralized web-entry (cost= computer with web interface)
  – Paper form – scannable (cost=scanner)
  – 3rd party software, e.g. GWTG
  – Downloadable from hospital information management systems
    • (cost depends on system – currently evaluating MIDAS, EPIC)
Iowa Stroke Registry

Welcome to the Iowa Stroke Registry

Use of a Registry to Improve Acute Stroke Care

Paul Coverdell National Acute Stroke Registry Surveillance

Million Hearts: Strategies to Reduce the Prevalence of Leading Cardiovascular Disease Risk Factors - United States, 2011

Prevalence of Stroke - United States - 2006-2010

Stroke - Educational Materials for Professionals

Informational Slide Shows
  Coverdell Registry  Iowa Stroke Registry  Registry Data - July 2012

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Iowa Stroke Registry Use

- System performance
- Component performance
- Comparison to state and national performance
- Quality Improvement
  - System Organization
  - System Process
  - Education
    - Tool kits
    - Lean
Iowa Stroke Registry Value

• Focused on patient care and outcome
• Up-to-date evaluation of performance
  – Last patient entered
  – Impact on next patient
• Linking across continuum of care
• Can provide timely information for care
• Stroke network of providers
Benefits of Participating in the ISR

• Development of a Stroke System
• Encouragement to hospitals to network with one another
• Opportunity to contribute to improve stroke care quality statewide
• Great resources and mentoring for hospitals needing specific stroke related information
• Data collection through uniform procedures suitable for each hospital
• Part of an important federally-funded project
• Easy access to automated data reports on your own hospital with comparable state data
• Annual training meetings to exchange best practices and network with colleagues statewide
• Access to webinars and educational information as part of federal and state network
Benefits for the Patient

• Recognition and diagnosis
• Provide optimal treatment
• Promote recovery
• Decrease death and disability
• Prevent re-hospitalization
• Prevent recurrence