

Structure and Use of Healthcare Registries

Manish Kharche, Graduate Research Assistant
Lanis L. Hicks, Professor & Interim Chair
Department of Health Management and
Informatics
University of Missouri

January 18, 2011



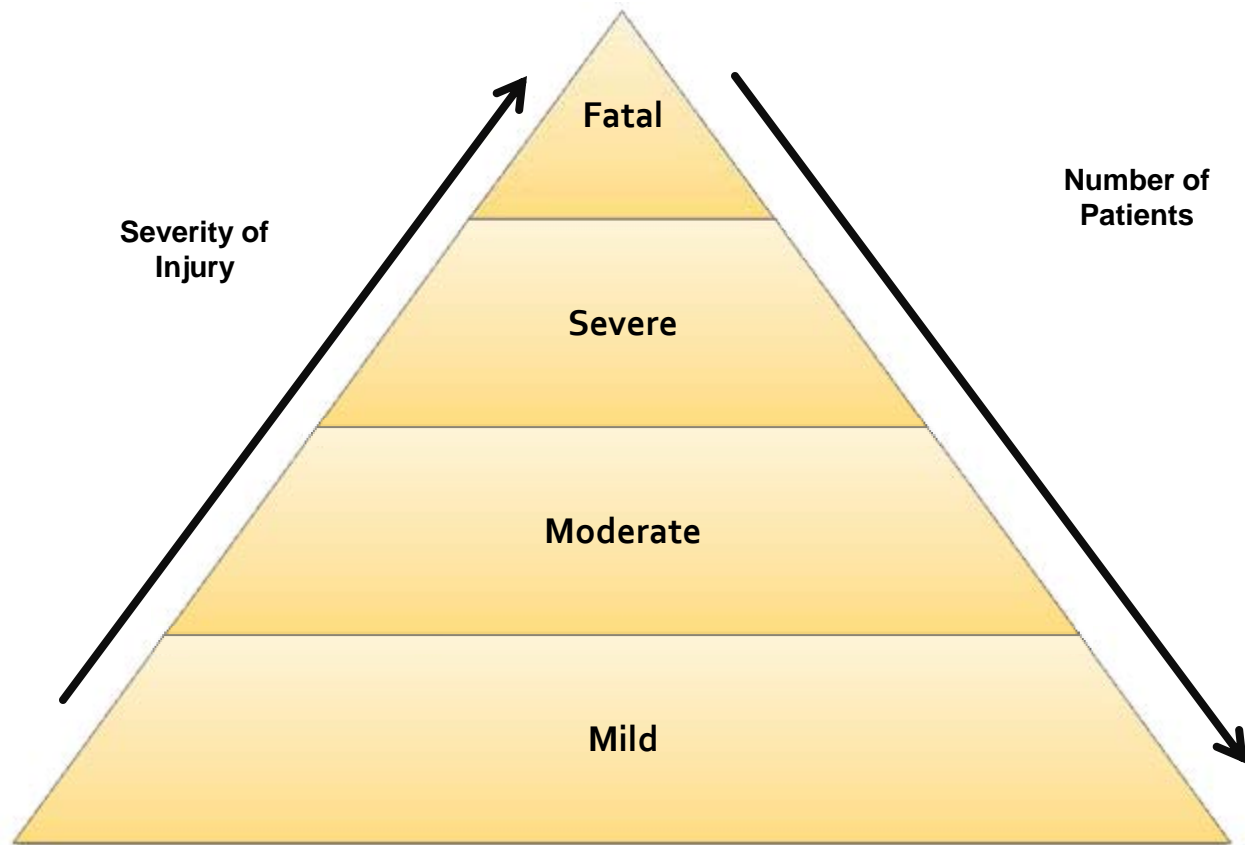
Introduction

- Lessons learned in Vietnam War led to dramatic changes in the care of the injured in the US in the 1970s and 1980s
- Upon return from war, medical personnel pointed out that “ A soldier injured in jungles of South East Asia had better chances of survival that those injured in road traffic accidents”
- This led to formation of Trauma Centers, Trauma Center Standards, and Trauma System development and proliferation in those two decades
- First computerized trauma database on mainframe computers was developed in 1969 at Cook County Memorial Hospital, Chicago, which become the prototype for Illinois Trauma Registry
- In 2006, there were 37 states that maintained trauma registries with data on patients treated

Trauma Fact Sheet

- Number of trauma patients benefiting from a Regional Trauma Center - 678,000
- Severity Adjusted National Norm per patient cost - \$14,896
- Total Trauma Center cost – estimated to be \$10.1 billion
- Total loss – estimated to be \$1 billion
- Annual direct and indirect trauma cost is estimated between \$100 and \$200 billion
- Each year, 8 to 9 million people suffer disabling injury
- Of those, 3 million will be permanently disabled
- Trauma is the leading cause of death for individuals under the age of 45 in US
- There are 150,000 trauma deaths in US each year
- Health care institutions in US handle an estimated 3,000,000 trauma cases annually

Injury Pyramid



Stroke Fact Sheet

- Stroke is America's 3rd leading cause of death after Heart Diseases and Cancer
- Stroke is a leading cause of severe long-term physical and mental disability
- Every 40 seconds someone in America has a stroke
- Stroke prevalence was about 64 million in adults age 20 or older
- Over 40 million US adult live today with effects of a stroke
- Stroke-related medical costs and disability were \$73.7 billion in 2010
- Women account for about 6 in 10 stroke deaths
- Each year, about 795,000 people suffer new or recurrent stroke; of these 610,000 are new cases and 185,000 are recurrent cases
- Stroke kills more than 137,119 people a year

STEMI Fact Sheet

- According to the American Heart Association, around 17.6 million people in the US have one or more form of Coronary Heart Disease (CHD)
- Of that population, 8.5 million people have **Myocardial Infarction (MI)**
- In the US adults age 20 and older, the prevalence of MI is 3.6%
- The annual incidence of heart attack is 935,000; there are 610,000 new cases and 325,000 recurrent attacks
- Mortality, in 2006, was 141,462
- In 2008, the estimated direct and indirect cost of coronary artery disease in the US was \$475.3 billion
- Every 25 seconds someone in US will suffer a coronary event
- About every minute someone will die from a coronary event

Age Adjusted Death Rates: 2006

Top Ten States and Missouri

| Sl. No. | Trauma | Rate |
|-----------|-----------------|-------------|
| 1 | New Mexico | 67.1 |
| 2 | Mississippi | 63.8 |
| 3 | West Virginia | 62.2 |
| 4 | Wyoming | 58.9 |
| 5 | Kentucky | 57.5 |
| 6 | Louisiana | 56.6 |
| 7 | Oklahoma | 56.3 |
| 8 | Montana | 55.8 |
| 9 | Tennessee | 54.2 |
| 10 | Alabama | 53.8 |
| 15 | Missouri | 49.7 |

| Sl. No. | Stroke | Rate |
|-----------|-----------------|-------------|
| 1 | Arkansas | 58.8 |
| 2 | Alabama | 55.3 |
| 3 | Tennessee | 54.9 |
| 4 | Mississippi | 53.4 |
| 5 | Oklahoma | 53.4 |
| 6 | North Carolina | 52.4 |
| 7 | Idaho | 51.8 |
| 8 | South Carolina | 51.6 |
| 9 | Louisiana | 51.5 |
| 10 | Georgia | 51.3 |
| 12 | Missouri | 49.5 |

| Sl. No. | Heart Disease | Rate |
|-----------|-----------------|--------------|
| 1 | Mississippi | 270.9 |
| 2 | Alabama | 253.3 |
| 3 | Oklahoma | 251.1 |
| 4 | West Virginia | 236.9 |
| 5 | Kentucky | 235.5 |
| 6 | Tennessee | 233.3 |
| 7 | New York | 233.1 |
| 8 | Arkansas | 233.0 |
| 9 | Louisiana | 232.3 |
| 10 | Michigan | 227.0 |
| 12 | Missouri | 224.4 |

Missouri Data on Age Adjusted Death Rates, 2005

| | Trauma | Stroke | Heart Disease |
|---------------------------------|--------|------------------------------|-------------------------------------|
| Death rate in MO | 47.4 | 52.6 | 235.5 |
| US Rate | 39.1 | 46.6 | 211.1 |
| % change from 2004 to 2005 (MO) | +1.3% | -3.4% | -12.9% |
| Missouri Rank | 16 | 13 | 11 |
| Hospitalizations | | 76,466 (Mortality - 24.3) | 27,390 (STEMI) (Mortality - 8.9) |
| Emergency Department visits | | 24,964 (Mortality - 0.8) | 4,478 (STEMI) (Mortality - 0.1) |

Source: <http://www.cdc.gov/nchs/pressroom/data/Missouriog.pdf>

Higher rank means more deaths. Age adjusted death rates (per 100,000) were used as the basis of comparison. Age-adjusted death rates eliminate the bias of age in the makeup of the populations being compared, thereby providing a much more reliable rate for comparison purposes.

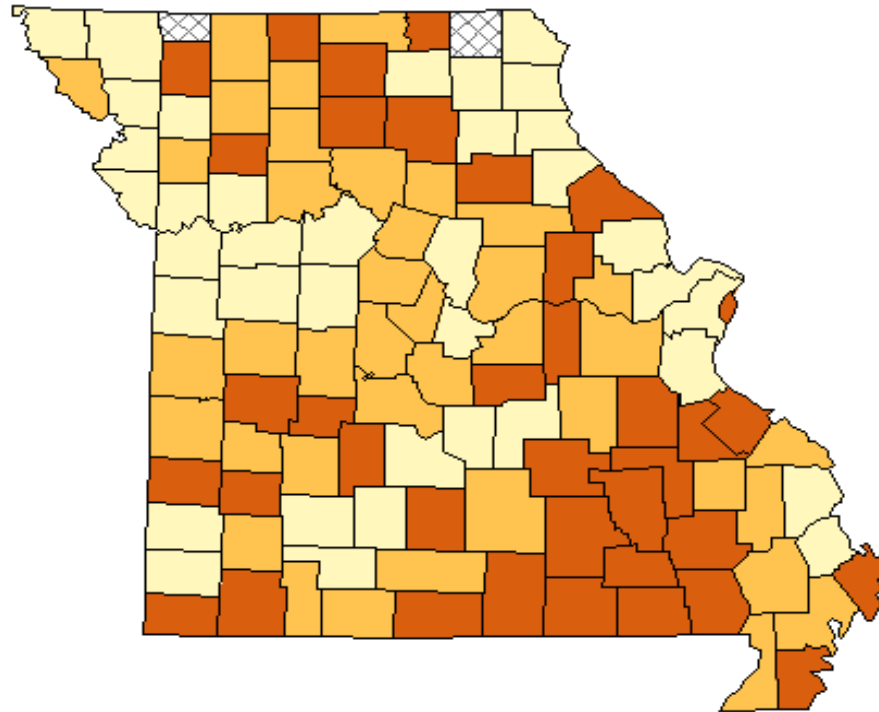
2000-2006, Missouri

Death Rates per 100,000 Population

All Injury, All Intents, All Races, All Ethnicities, Both Sexes, All Ages

Annualized Crude Rate for Missouri: 67.91

Missouri Estimated Average Annual Medical Costs of \$35,442,655 and Work Loss Costs of \$2,653,716,491



Suppressed/undefined



44.87-71.53



71.54-87.94



87.95-157.05

Reports for All Ages include those of unknown age.

* Rates based on 20 or fewer deaths may be unstable. These rates are suppressed for counties (see legend above); such rates in the title have an asterisk.

Medical and work loss cost estimates are expressed in year 2005 dollars.

Cost estimates are not comparable across states; county-level cost estimates should only be used for comparisons within this state.

Produced by: Office of Statistics & Programming, National Center for Injury Prevention & Control, CDC

Data Sources: NCHS National Vital Statistics System for numbers of deaths; US Census Bureau for population estimates.

01/18/2011

Health Management & Informatics, University of Missouri

Need for Registry

- A well-designed registry assists health care providers, policymakers, and community organizations in establishing a coordinated approach to care and injury prevention
- Provides a resource for clinical benchmarking, process improvement, and patient safety
- Characterizes patient care across regions
- Provides baseline measures for enhancing disaster preparedness
- Develops better injury scoring and outcome measures
- Evaluates and improves the timeliness, appropriateness, and quality of patient care

Need for Registry

- Provides a mechanism for comparing patient outcomes across service areas, provider groups, etc.
- Identifies excessively hazardous environments (e.g., specific auto intersections);
- Set priorities and evaluates public health interventions relating to injury prevention
- Identifies disease trends by geographic location, hospital length of stay, etc.
- Provides data for clinical benchmarking, process improvement, and patient safety
- Provides the capability to monitor disease system trends

CHARACTERISTICS OF AN IDEAL REGISTRY

According to Institute of Healthcare Improvement (IHI)

- “A registry is a system that records patient care information and data; providers can use the registry to record the critical elements of the treatment plan, can reproduce quick care summaries at the time of a visit, and can enter data to alter the care plan as needed.”
- “A **disease registry** is a collection of secondary data related to patients including demographic details, a specific diagnosis, condition, or procedure, treatment, outcome and follow-up.”

CHARACTERISTICS OF AN IDEAL REGISTRY

Characteristics of a registry:

- The type of registry electronic, manual or combined.
- Data integrity, availability, quality, security, data transaction.
- Documentation of all the process and procedures for developing and running the registry.
- Including stake holders of the registry to ensure only essential data and data elements are included.
- Keeping manual data entry to minimum to avoid mistakes and bad data.
- Identifying the members to handle the workload or provide stakeholders with training.
- Updating registry at regular intervals to maintain data accuracy
- Ensuring patient data confidentiality with multiple levels of security

REGISTRY FUNCTIONS

- Patient Care Evaluation
- Performance and Quality Improvement
- Trauma, STEMI, or Stroke Center Accreditation
- Clinical and System Research
- Disease Prevention Initiatives and Research
- Administrative Support/Financial Decision Making

Time Critical Diagnosis – Management Information System

- The Time Critical Diagnosis – Management Information System (TCD-MIS) is a comprehensive, coordinated statewide and regional network
- It helps in the delivery of emergency medical care under one banner rather than through three separate systems
- It allows resource savings, resource sharing, and coordination at different levels
- TCD-MIS aims to –
 - Improve Patient Outcomes and Saves Lives
 - Improve Hospital Outcomes
 - Improve Regional Outcomes
- **Department of Health and Senior Services (DHSS) is working to enhance the trauma arm and establish the stroke and STEMI arms of the TCD system**

TCD-MIS

Why Do We Need This?

- A TCD-MIS is envisioned as forming the foundation for continual evaluation and performance improvement
- Effective communication of time-critical information is important in improving outcomes in health care
- A well-constructed and populated management information system can serve to promote change within the system

TCD-MIS

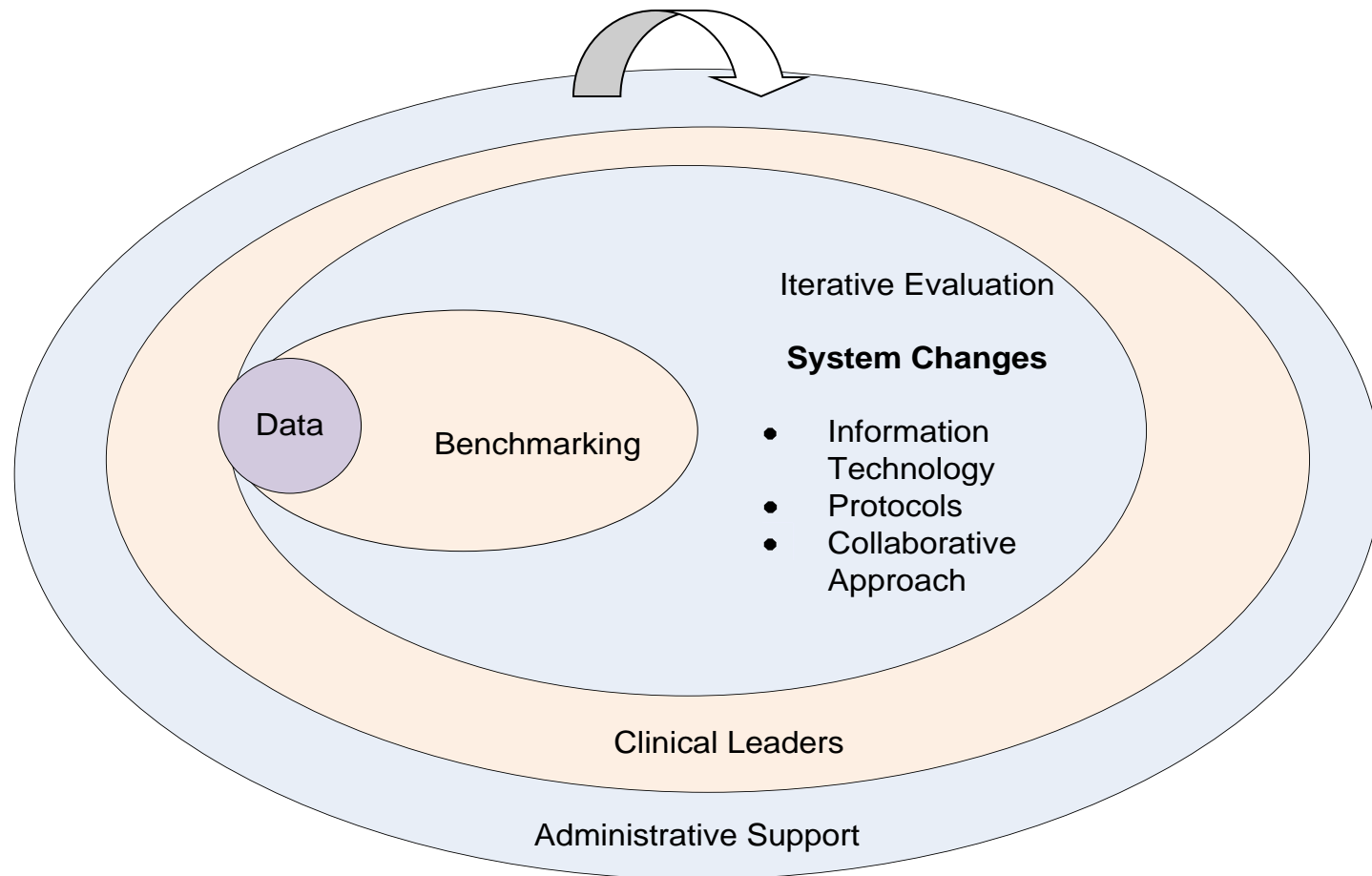
Why Do We Need This?

- The purpose of a management information system is to support quality improvement functions, not only within the Agency, but also on an institutional, regional, and statewide basis
- A combined system can provide more information for decision making and minimize the demands on organizations

Missouri Current Status

- Designated Trauma Centers in Missouri
 - Level I Trauma Centers - 10, including 3 pediatric trauma centers
 - Level II Trauma Centers - 11
 - Level III Trauma Centers - 7
- Stroke Centers - 14 designated by the Joint Commission
- The State of Missouri in the process of writing rules and regulations, and is working towards the goal of center designation

ROLE OF DATA AND BENCHMARKING IN QUALITY IMPROVEMENT



National Trauma Data Bank

- Largest aggregation of US trauma data, with a growing knowledge base
- States report to the NTDB and can gain access to a variety of reports that can be used for their own performance improvement
- To standardize data elements in the NTDB, the National Trauma Data Standard (NTDS) was created
- NTDS data dictionary is designed to establish a national standard for exchange of trauma registry data
- Local and regional registries will have additional data points or elements, as well as additional response codes, beyond the captured data according to NTDS data standard.

States and Trauma registries

source- www.ntdsdictionary.org

- States and Trauma Registries
 - 32 states have statewide registries
 - 13 states (and DC) are discussing, planning, or developing a registry
 - 5 states have no plans for a registry currently

- Out of 32 state registries -
 - 27 require hospitals to report
 - 11 states...all acute care hospitals
 - 15 states...only designated centers
 - 1 state...only participating hospitals
 - 5 request hospitals to report
 - 2 states...all acute care hospitals
 - 1 state...only designated centers
 - 2 states...partial registries

Trauma Registry

- An effective trauma registry requires that a system be in place that supports data collection, submission, abstraction and verification of the completeness and accuracy of the data.
- Trauma registry provides a mechanism for overall patient care and system evaluation
- Major problem in establishing and maintaining an efficient and effective disease registry is **data integrity**
- Threats to data integrity
 - Elective Submission Impacts Completeness of Case Capture
 - Differences in Case Definition
 - Differences in Coding Conventions
 - Data inconsistencies and irregularities

Data Elements Characteristics

- Importance of the data elements to the integrity of the registry
- Their reliability
- Their necessity for the analysis of the primary outcomes
- Their contribution to the overall response burden
- The incremental cost associated with their collection
- Data elements for explicitly planned analysis of any particular importance, apart from the above mentioned characteristics

National Trauma Data Bank

National Trauma Data Standards

There are total of 82 data elements in the NTDS data dictionary, which are grouped under 10 main headings

1. Demographic Information – 12 elements
2. Injury Information – 16 elements
3. Pre- Hospital Information – 17 elements
4. Emergency Department Information – 20 elements
5. Hospital Procedure Information – 3 elements
6. Diagnosis Information – 2 elements
7. Injury Severity Information – 5 elements
8. Outcome Information – 5 elements
9. Financial Information – 1 element
10. Quality Assurance Information - 1 element

Missouri Trauma Data Registry

- Missouri has a comprehensive trauma data registry with more than 200 data elements (approximately 210)
- Of these data elements, 65 are required
- All the data elements are grouped under 11 main headings

1. Demographics - 29
2. Injury Information - 24
3. Pre-Hospital Information - 17
4. Referring Facility Information - 32
5. ED/Acute Care - 11
6. Initial Assessment - 41

7. Diagnosis - 5
8. Co-morbidity - 3
9. Procedures done - 9
10. Complications - 9/
Performance Improvement - 9
11. Outcome - 20

Recommended Data Elements

The following data elements are recommended by NTDB and the *Specifications Manual for National Hospital Inpatient Quality Measures*

- Median Time from ED Arrival to ED Departure for Admitted ED Patients
- Admit Decision Time to ED Departure Time for Admitted Patients
- Prophylactic antibiotic received within one hour prior to surgical incision
- Prophylactic antibiotic selection for surgical patients
- Prophylactic antibiotic discontinued within 24 hours after surgery end time

National Cardiovascular Data Registry - ACTION Registry

- Created by the merger of the National Cardiovascular Data Registry - ACTION Registry from the American College of Cardiology Foundation and the Get With The Guidelines - Coronary Artery Disease program from the American Heart Association
- They combined the best of both programs into a single, unified national registry
- It measures
 - Patient demographics, provider, and facility characteristics
 - Transfer facility therapies and reperfusion strategies
 - Adverse event rates
 - Compliance with ACC/AHA Clinical Guidelines recommendations
 - And more

National Cardiovascular Data Registry - ACTION Registry

There are 204 total data elements, which are grouped into 12 different headings

1. Demographics - 10
2. Admissions - 15
3. Cardiac Status at First Medical Contact - 13
4. History and Risk Factors - 18
5. Medications at Home - 42
6. Procedures and Test - 28

7. Reperfusion Strategy- 7
8. In hospital Clinical Events - 16
9. Laboratory Results - 28
10. Discharge - 14
11. Administration - 10
12. Optional Elements - 7

Missouri STEMI Data Registry

- Missouri proposed STEMI data registry could potentially be more than 190 data elements
- Only about 40 of these data elements are being recommended as being required by the state registry
- All the data elements are currently grouped under 12 different headings

1. Demographics - 21
2. Incident (Injury Location) - 7
3. Pre-Hospital - 15
4. Referring Facility - 29
5. ED/Acute Care - 10
6. STEMI Information - 4
7. Initial Assessment - 54

8. Diagnosis - 1
9. Comorbidity - 2
10. Procedures performed - 7
11. Complications and Performance Improvement Audits - 22
12. Outcome - 20

Recommended Data Elements

The following data elements are recommended by the *Specifications Manual for National Hospital Inpatient Quality Measures*

- Aspirin at Arrival
- Aspirin Prescribed at Discharge
- Angiotensin Converting Enzyme (ACE) Inhibitor or Angiotensin II Reception Blockers (ARB) for (Left Ventricular Systolic Dysfunction (LVSD)
- Beta-Blocker Prescribed at Discharge
- Median Time to Fibrinolysis
- Fibrinolytic Therapy Received Within 30 Minutes of Hospital Arrival
- Median Time to Primary PCI
- Primary PCI Received Within 90 Minutes of Hospital Arrival
- Inpatient Mortality
- Statin Prescribed at Discharge
- Lipid-Lowering Therapy at Discharge (Optional Test Measure)

Paul Coverdell National Acute Stroke Registry

- CDC, in consultation with stroke experts and organizations, piloted eight prototype registry projects, led by academic medical institutions across the country, to test models for measuring the quality of care delivered to stroke patients
- In June 2007, CDC expanded funding for the Paul Coverdell National Acute Stroke Registry
- Mission of PCNASR
 - 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 acute 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 for stroke surveillance within stroke systems of care

Paul Coverdell National Acute Stroke Registry

- All together, there are 167 data elements in the registry
- These 167 data elements are grouped under 12 different headings

1. Demographics - 6
2. Pre-hospital/EMS Data - 9
3. ED Data - 5
4. Hospital Admission Data - 8
5. Imaging - 6
6. Time of Sign and Symptoms - 11
7. Thrombolytic Treatment - 18

8. Reason for Not Giving tPA - 23
9. Medical History - 11
10. In-Hospital Procedures and Treatment - 25
11. Other In-hospital Complications - 4
12. Discharge Data - 41

Missouri State Stroke Registry

- Missouri Stroke Data Registry is a comprehensive data registry that could potentially include more than 290 data elements
- Of these data elements, only about 51 of these data elements are being recommended as being required by the state registry
- All the data elements are grouped under 13 headings

1. Demographics - 21
2. Incident - 8
3. Pre-Hospital - 15
4. Referring Hospital Information - 29
5. ED/Acute Care - 12
6. Stroke Information - 7
7. Initial Assessment - 54

8. Diagnosis - 19
9. Comorbidity - 6
10. Stroke History - 8
11. Procedures - 13
12. Complications/Performance Improvement - 22
13. Outcome - 26

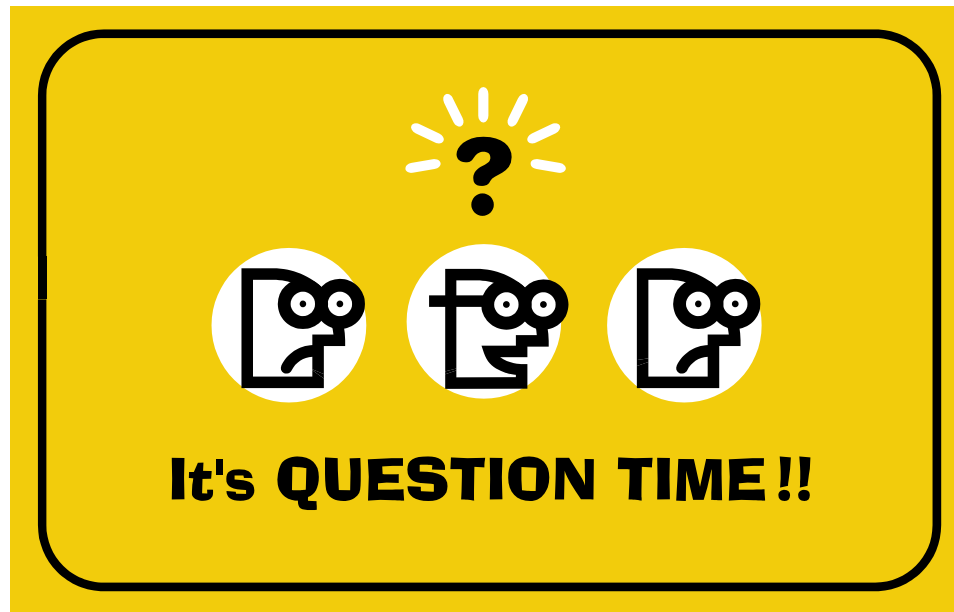
Recommended Data Elements

- The following data elements are recommended by the *Specifications Manual for National Hospital Inpatient Quality Measures*
 - Venous Thromboembolism (VTE) Prophylaxis
 - Discharged on Antithrombotic Therapy
 - Anticoagulation Therapy for Atrial Fibrillation/Flutter
 - Antithrombotic Therapy By End of Hospital Day 2
 - Discharged on Statin Medication
 - Stroke Education
 - Assessed for Rehabilitation

Major Problems of Registries

- Data Quality -- Bad data lead to errors in registry outcomes
- Funding sources -- Lack of a sustained source of funding results in problems in sustaining the registry functions
- Data collection methods -- Lack of uniform data collection methods lead to inconsistent and inaccuracy of data
- Data validation -- With data preprocessing this method ensures the quality of registry data.
- Data elements -- Data elements are the backbone of the registry and must be realistic and reasonable
 - They must represent the whole process of health care delivery
 - They should provide information about area for improvement

Questions or Comments?



Thank You