Existing Data Sources

GINA M. BERG, PHD, MBA

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Disclosure

No financial disclosures
No clinical/product recommendations
No off-label uses
No HIPAA information
Public information
Special Thanks

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PTS Research Committee
### National Trauma Data Bank

#### Research Datasets (RDS)
- All records sent to NTDB
  - >6 million cases
  - >900 trauma centers
- **Convenience sample**
  - Larger hospitals more severely injured
- Viable for rare events or small cohorts
  - Large numbers
- Not valid for national inferences about incidence
- $300/dataset

#### National Sample Program (NSP)
- Nationally representative sample
  - 100 Level 1 and II hospitals
  - Stratified on US Census region, level and NTDB reporting status
  - Data weighted
- Appropriate for national estimates or yearly comparisons
- $300/dataset

ACS NTDB NSP, 2011
NTDB Research Data Set

National Trauma Data Bank® (NTDB®) research data may be used for informational and research purposes with approval from the American College of Surgeons (ACS) Committee on Trauma. If you would like to request permission to reproduce NTDB tables or graphs or use the NTDB dataset for scientific analysis, you must complete our online data application below and agree to our Terms and Conditions.

Directions for Ordering Research Data

Apply for the NTDB Research Data Set

The NTDB committee will review your application, and you will be notified of their approval. Please contact us with any questions you may have about this process at ntdb@facs.org

Fee Schedule

<table>
<thead>
<tr>
<th>Description</th>
<th>Research Datasets (RDS)</th>
<th>Reprints from Publications</th>
<th>AIS 2005 table</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contains all records sent to NTDB for specified admission years.</td>
<td></td>
<td></td>
<td>AIS 2005 (2008 update) data table</td>
</tr>
<tr>
<td>Explores data on pediatric patients, Level III, IV, V, or undesignated trauma centers.</td>
<td></td>
<td></td>
<td>Latest AIS data available.</td>
</tr>
<tr>
<td>Valuable for looking at a small patient cohort because the overall number of patients is much larger.</td>
<td></td>
<td></td>
<td>Available for admission years 2007-2015</td>
</tr>
<tr>
<td>Not appropriate for making national estimates or yearly comparisons.</td>
<td></td>
<td></td>
<td>More Information on AIS.</td>
</tr>
</tbody>
</table>

Fees

- $3000/dataset

Documentation

- Archived NTDB RDS User Manuals (ZIP)

https://www.facs.org/quality-programs/trauma/tqp/center-programs/ntdb/datasets
Healthcare Cost and Utilization (HCUP)

Family of Healthcare Databases
- Inpatient, emergency department and ambulatory surgery
- Hospital billing data
- All-payer
- Longitudinal multi-year
- HCUP Partners
## Healthcare Cost and Utilization (HCUP) National Databases

<table>
<thead>
<tr>
<th>Database</th>
<th>Year</th>
<th>Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Inpatient Sample (NIS)</td>
<td>1988</td>
<td>• &gt; 7 million hospital stays annually (20% US hospitals)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Utilization, access, charges, quality, and outcomes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Released annually</td>
</tr>
<tr>
<td>Kid’s Inpatient Database (KID)</td>
<td>1997</td>
<td>• Age &lt;20</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 2-3 million per year; weighted estimates 7 million</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Utilization, access, charges, quality, and outcomes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Released every three years</td>
</tr>
<tr>
<td>Nationwide Emergency Department Sample (NEDS)</td>
<td>2006</td>
<td>• Study conditions related to ED use</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• ~ 30 million ED visits</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Released annually</td>
</tr>
<tr>
<td>Nationwide Readmissions Database (NRD)</td>
<td>2010</td>
<td>• National readmission rates for all payers and the uninsured</td>
</tr>
</tbody>
</table>

**All data sampled from participating HCUP States**
# Healthcare Cost and Utilization (HCUP) National Databases

<table>
<thead>
<tr>
<th>Database</th>
<th>Demographics</th>
<th>Injury Related</th>
<th>Diagnoses</th>
<th>Procedures</th>
<th>Severity</th>
<th>Co-morbidity</th>
<th>Discharge</th>
<th>LOS</th>
<th>Total Charges</th>
<th>Expected Payer</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIS</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>KID</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>NEDS</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
## Healthcare Cost and Utilization (HCUP) National Databases

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>NIS</td>
<td>All Others</td>
<td>☐ $625</td>
<td>☐ $500</td>
<td>☐ $500</td>
<td>☐ $350</td>
<td>☐ $350</td>
<td>☐ $350</td>
<td>☐ $350</td>
</tr>
<tr>
<td>Nationwide</td>
<td>NIS</td>
<td>Students</td>
<td>☐ $125</td>
<td>☐ $100</td>
<td>☐ $100</td>
<td>☐ $50</td>
<td>☐ $50</td>
<td>☐ $50</td>
<td>☐ $50</td>
</tr>
<tr>
<td>Nationwide</td>
<td>KID</td>
<td>All Others</td>
<td>☐ $500</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>☐ $350</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Nationwide</td>
<td>KID</td>
<td>Students</td>
<td>☐ $100</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>☐ $50</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Nationwide</td>
<td>NEDS</td>
<td>All Others</td>
<td>☐ $1,000</td>
<td>☐ $750</td>
<td>☐ $750</td>
<td>☐ $500</td>
<td>☐ $500</td>
<td>☐ $500</td>
<td>☐ $500</td>
</tr>
<tr>
<td>Nationwide</td>
<td>NEDS</td>
<td>Students</td>
<td>☐ $200</td>
<td>☐ $150</td>
<td>☐ $150</td>
<td>☐ $75</td>
<td>☐ $75</td>
<td>☐ $75</td>
<td>☐ $75</td>
</tr>
<tr>
<td>Nationwide</td>
<td>NRD</td>
<td>All Others</td>
<td>☐ $1,000</td>
<td>☐ $1,000</td>
<td>☐ $750</td>
<td>☐ $500</td>
<td>☐ $500</td>
<td>☐ $500</td>
<td>☐ $500</td>
</tr>
<tr>
<td>Nationwide</td>
<td>NRD</td>
<td>Students</td>
<td>☐ $200</td>
<td>☐ $200</td>
<td>☐ $150</td>
<td>☐ $75</td>
<td>☐ $75</td>
<td>☐ $75</td>
<td>☐ $75</td>
</tr>
</tbody>
</table>


Note: Nationwide databases are delivered via download only.

https://www.hcup-us.ahrq.gov/db/nation/nis/nisdbdodocumentation.jsp
Healthcare Cost and Utilization (HCUP) National Databases

NIS Database Documentation

The National ( Nationwide) Inpatient Sample (NIS) is the largest all-payer inpatient care database in the United States, containing data on more than seven million hospital stays. Its large sample size is ideal for developing national and regional estimates and enables analyses of rare conditions, uncommon treatments, and special populations.

The following links provide detailed documentation for the NIS, from a high-level Overview to all the detailed specifications, restrictions, and resources necessary for researchers working and publishing with the NIS.

Description of NIS Database
- NIS Overview
- HCUP Partners in the NIS
- Introduction to the NIS
  - 2016 (PDF file, 658 KB; HTML)
  - Prior Years
- NIS Related Reports
  - Prior Years
  - Checklist for Working With the NIS

Restrictions on Use
- HCUP Data Use Agreement Training
- Data Use Agreement for the National ( Nationwide) Databases (PDF file, 86 KB; HTML)
- Requirements for Publishing with HCUP Data

File Specifications and Load Programs
- NIS File Specifications
  - Nationwide SAS Load Programs
  - Nationwide EPIC Load Programs
  - Nationwide State Load Programs

Data Elements
- NIS Description of Data Elements
  - Prior Years
  - NIS Summary Statistics
  - Prior to Data Year 2012
    - Availability of AHCA Hospital Identifiers
    - Why the NIS should not be used to make State-level estimates

Additional Resources for Data Elements
- NIS Severity Measures
  - Overview of Severity Measures (PDF file, 60 KB; HTML)
  - Inpatient Severity Measures (SAP file, 683 KB; SAV file, 84 MB)
  - Nationwide Readmission Dataset (SAP file, 93 MB; SAV file, 173 MB)
  - National Readmission Database (SAP file, 1.3 GB; SAV file, 2.5 GB)
  - All-Payer State Inpatient Databases (SAP file, 30.8 GB; SAV file, 61 GB)

ICD-10-CM/PCS Data Included in 2015-2016 NIS
- 2015 NIS Revised File Structure and Data Elements (PDF file, 171 KB)
- Caution: 2015 NIS includes ICD-9-CM and ICD-10-CM/PCS
  + 2015 NIS Revised File Structure and Data Elements (PDF file, 304 KB)
- Additional ICD-10-CM/PCS Resources
- Tutorial for Loading HCUP Software Tools for ICD-10-CM/PCS

2012 NIS Redesign
- 2012 NIS Redesign Report (PDF file, 2.0 MB)

Trend Weights for the 1992-2011 NIS for Consistent Estimates with the Redesigned NIS

Known Data Issues
- Why the NIS should not be used to make State-level estimates
  - 2011
  - 2009
  - 1998-1999
  - 1994-1997
  - 1993
  - 1998-1992

NIS Supplemental Files
- Cost-to-Charge Ratio Files
- Hospital Market Structure (HMS) Files
- 1993-2011 NIS Supplemental Discharge-Level Files
- NIS Hospital Ownership Files

HCUP Tools: Labels and Formats
- Clinical Classifications Software (CCS)
  - Format Programs
    - CCS Formats Program (TXT file, 1.5 MB) Creates SAS formats to label clinical classifications

https://www.hcup-us.ahrq.gov/db/nation/nis/nisdbdocumentation.jsp
## Healthcare Cost and Utilization (HCUP) State Databases

<table>
<thead>
<tr>
<th>Database</th>
<th>Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>State Inpatient Databases (SID)</td>
<td>• Hospital inpatient discharge information</td>
</tr>
</tbody>
</table>
| State Ambulatory Surgery and Services Databases (SASD) | • Encounter-level data for ambulatory surgery and other outpatient services  
• Hospital-owned facilities  
• Some nonhospital-owned facilities                                                        |
| State Emergency Department Databases (SEDD)   | • Discharge information on all ED visits that do not result in hospital admission                                                |

**All data from participating HCUP States**
## CDC Data

<table>
<thead>
<tr>
<th>Database</th>
<th>Injury or Mortality</th>
<th>Data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WISQARS™</strong>&lt;br&gt;Web-based Injury Statistics Query and Reporting System</td>
<td>Interactive database system that provides customized reports of injury-related data</td>
<td>• Fatal injury&lt;br&gt;• Nonfatal injury&lt;br&gt;• Violent deaths&lt;br&gt;• Cost of injury data&lt;br&gt;• Fatal injury mapping</td>
</tr>
<tr>
<td><strong>Wonder</strong>&lt;br&gt;Series of online databases</td>
<td>Cause of death&lt;br&gt;Multiple causes of death</td>
<td>• Death certificates&lt;br&gt;• All US counties&lt;br&gt;• Single underlying cause of death&lt;br&gt;• Demographic data</td>
</tr>
<tr>
<td><strong>Vital Statistics</strong></td>
<td>Mortality data&lt;br&gt;Circumstances of injuries</td>
<td>• Customizable reports&lt;br&gt;• Downloadable Data</td>
</tr>
<tr>
<td><strong>National Death Index</strong></td>
<td>Centralized database of death record information</td>
<td>• Determine if persons in study have died</td>
</tr>
</tbody>
</table>

[http://www.cdc.gov](http://www.cdc.gov)
2008-2014, United States
Death Rates per 100,000 Population
Fall, Unintentional, All Races, All Ethnicities, Both Sexes, All Ages
Annualized Crude Rate for United States: 8.86

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.

Produced by: the Statistics, Programming & Economics Branch, National Center for Injury Prevention & Control, CDC
Data Sources: NCHS National Vital Statistics System for numbers of deaths; US Census Bureau for population estimates.

2008-2014, Kansas
Death Rates per 100,000 Population
Fall, Unintentional, All Races, All Ethnicities, Both Sexes, Ages 55 thru 85+ Years
Annualized Crude Rate for Kansas: 43.46

Produced by: the Statistics, Programming & Economics Branch, National Center for Injury Prevention & Control, CDC
Data Sources: NCVS National Vital Statistics System for numbers of deaths; US Census Bureau for population estimates.

National Electronic Injury Surveillance System (NEISS)

• Collect data on consumer product-related injuries
• Over 45 years
• Patient information
  • NEISS hospital
  • Every emergency visit associated with consumer product
• National probability sample of hospitals in the US and territories

<table>
<thead>
<tr>
<th>Product Grouping</th>
<th>Estimated Number</th>
<th>CV</th>
<th>Actual # Injuries</th>
<th>0-4</th>
<th>65+</th>
<th>Treat &amp; Release</th>
</tr>
</thead>
<tbody>
<tr>
<td>Toys</td>
<td>251,366</td>
<td>.03</td>
<td>8,329</td>
<td>89,483</td>
<td>7,599</td>
<td>242,690</td>
</tr>
<tr>
<td>Exercise Equipment</td>
<td>526,350</td>
<td>.10</td>
<td>12,899</td>
<td>17,871</td>
<td>72,052</td>
<td>483,067</td>
</tr>
<tr>
<td>Clothing</td>
<td>417,306</td>
<td>.09</td>
<td>10,034</td>
<td>18,657</td>
<td>112,410</td>
<td>373,157</td>
</tr>
</tbody>
</table>

https://www.cpsc.gov/Research-Statistics/NEISS-Injury-Data
ACS TQIP

• 825 participating trauma centers
• Feedback for improved care (risk-adjusted benchmarking)
• Data Dictionary (Information regarding)
  • Demographic
  • Injury & severity
  • Prehospital care
  • Emergency Department care
  • Hospital procedure
  • Diagnosis
  • Outcome
  • Financial
  • Quality assurance
  • Process of care
  • Surgeon specific reporting
National Burn Repository

- Annual report by American Burn Association
- Burn centers US & International
- Epidemiology of thermal injuries
- Demographics, injury information, outcomes & quality data

Used to:
- Answer clinical questions
- Answer research questions
- Compare performance of individual burn centers

- 205,033 patient records
- 96 US & 6 International
<table>
<thead>
<tr>
<th>Database</th>
<th>Sources of Injury Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Trauma Research Repository</td>
<td>Shared data sets (Coalition for National Trauma Research)</td>
</tr>
<tr>
<td>Pediatric Health Information System</td>
<td>Comparative database with clinical and resource utilization</td>
</tr>
<tr>
<td>Fatality Analysis Reporting System</td>
<td>Overall measure of highway safety (National Highway Traffic Safety Administration)</td>
</tr>
<tr>
<td>Center for Medicare and Medicaid Services Research Identifiable Files (CDC RIF)</td>
<td>Actual files with PHI. Research protocol and DUA. CMS.gov</td>
</tr>
<tr>
<td>Medicaid Analytic Extract (MAX) Data</td>
<td>Person level data files on Medicaid eligibility, service utilization and payments.</td>
</tr>
<tr>
<td>National Emergency Medical Services Information System (NEMSIS)</td>
<td>National effort to standardize EMS data NEMSIS.org</td>
</tr>
<tr>
<td>Virtual Pediatric Systems (VPS)</td>
<td>Severity adjusted critical care data for QI</td>
</tr>
<tr>
<td>Uniform Data System for Medical Rehabilitation (UDSMR)</td>
<td>Largest most comprehensive post acute care data.</td>
</tr>
<tr>
<td>DoD Trauma Registry</td>
<td>Selected data elements for trauma population.</td>
</tr>
<tr>
<td>Military Health System (MHS) Data Repository (MDR) and MHS Data Mart (M2)</td>
<td>Data repository for Defense Health Agency health care data.</td>
</tr>
<tr>
<td>DoD Birth and Infant Health Registry</td>
<td>Surveillance of health outcomes in military families (pregnancy and infant).</td>
</tr>
<tr>
<td>Surveillance System</td>
<td>Sources of Injury Data</td>
</tr>
<tr>
<td>------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>National Vital Statistics System (NVSS)</td>
<td>Vital Statistics Record</td>
</tr>
<tr>
<td>National Ambulatory Medical Care Survey (NAMCS)</td>
<td>Physician Record</td>
</tr>
<tr>
<td>National Hospital Discharge Survey (NHDS)</td>
<td>Hospital Discharge Record</td>
</tr>
<tr>
<td>National Hospital Care Survey (NHCS)</td>
<td>Inpatient hospital discharge, emergency department, outpatient, ambulatory surgery</td>
</tr>
<tr>
<td>National Hospital Ambulatory Medical Care Survey (NHAMCS)</td>
<td>ED Record, Outpatient Record</td>
</tr>
<tr>
<td>National Health Interview Survey (NHIS)</td>
<td>Telephone or In-person Interview</td>
</tr>
<tr>
<td>National Electronic Injury Surveillance System (NEISS &amp; NEISS-AIP)</td>
<td>ED Record</td>
</tr>
<tr>
<td>National Automotive Sampling System (NASS-GES)</td>
<td>Police Report</td>
</tr>
<tr>
<td>Fatality Analysis Reporting System (FARS)</td>
<td>EMS Record, ED Record, Medical Examiner, Police Report, Vital Statistics</td>
</tr>
<tr>
<td>Behavioral Risk Factor Surveillance System (BRFSS)</td>
<td>Telephone Interview</td>
</tr>
<tr>
<td>National Crime Victimization Survey (NCVS)</td>
<td>Telephone or In-person Interview</td>
</tr>
<tr>
<td>National Violent Death Reporting System (NVDRS)</td>
<td>Death certificates, coroner/medical examiner reports, police reports &amp; crime laboratories</td>
</tr>
</tbody>
</table>

**Provided by Stephen Strotmeyer, PhD, MPH at CHP/University of Pittsburgh**
# Canada Data Sources

<table>
<thead>
<tr>
<th>CANADA</th>
<th>Data</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Trauma Registry (NTR)*</td>
<td>Information on injury and trauma</td>
<td>NTDB</td>
</tr>
<tr>
<td>Comprehensive Dataset (CDS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minimal Dataset (MDS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statistics Canada</td>
<td>Causes of death</td>
<td>CDC</td>
</tr>
<tr>
<td>National Ambulatory Care Reporting System (NACRS)</td>
<td>Hospital- and Community-based ambulatory care</td>
<td>HCUP</td>
</tr>
<tr>
<td>Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP)</td>
<td>Injury and poisoning surveillance system</td>
<td>NEISS</td>
</tr>
<tr>
<td>*Canadian Institute for Health Information (CIHI)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Canadian Institute for Health Information (CIHI)

Source: Natalie Yanchar, MD
## Additional Canada Data Sources

<table>
<thead>
<tr>
<th>Database</th>
<th>Sources of Injury Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transport Canada National Collision Database</td>
<td>Dataset on all police-reported MVCs on public roads</td>
</tr>
<tr>
<td>Canadian Red Cross Unintentional Water-Related Fatalities Database</td>
<td>Unintentional fatal drownings: demographics and circumstances</td>
</tr>
<tr>
<td>Rick Hansen Spinal Cord Injury Registry</td>
<td>Experiences and outcomes of people with traumatic SCI: causes, extent of injury, level of paralysis, recovery, treatment options</td>
</tr>
<tr>
<td>Association of Workers’ Compensation Boards of Canada</td>
<td>Data on occupational injuries resulting in lost time claims or fatalities</td>
</tr>
</tbody>
</table>

Source: Natalie Yanchar, MD
# Research Committee Members

<table>
<thead>
<tr>
<th>Database</th>
<th>Investigator</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pancreatic Injuries</strong></td>
<td>Bindi Naik-Mathuria, MD, MPH</td>
</tr>
<tr>
<td>Prospective Observational</td>
<td>University of Texas Children’s Hospital</td>
</tr>
<tr>
<td><strong>Vascular Injuries</strong></td>
<td>Bindi Naik-Mathuria, MD, MPH</td>
</tr>
<tr>
<td>Prospective Observational (Development)</td>
<td>University of Texas Children’s Hospital</td>
</tr>
</tbody>
</table>
| **Topic of Your Interest**                    | Your Name Here                                                              

Considerations

Many existing data sources
- Question dependent
- Population to be studied
- Provides both the numerator and denominator needed

Costs
- Variable

Statistical considerations
- Some require weighting or specific software (SAS, R)
- Statistical support for cleaning and analysis

Limitations
- Selection bias (contributors)
- Coding consistency
- Missing data
- Data focus
- Oct 2015 transition from ICD9 to ICD10

Generalizability

Previously published literature

“Here’s a list of 100,000 warehouses full of data. I’d like you to condense them down to one meaningful warehouse.”
Thank You

gberg@kumc.edu

Professor Herman stopped when he heard that unmistakable thud — another brain had imploded.
Resources

• National Trauma Databank (NTDB)
  https://www.facs.org/qualityprograms/trauma/ntdb/datasets

• AHRQ HealthCare Cost Utilization (HCUP)
  https://www.facs.org/quality-programs/trauma/ntdb/datasets

• Center for Disease Control (CDC)
  https://www.cdc.gov/nchs/data_access/ftp_data.htm

• Consumer Product Safety Commission (CPSC)
  https://www.cpsc.gov/Research--Statistics/NEISS-Injury-Data