Data Intersections

Malia Villegas
Director, NCAI Policy Research Center
July 23, 2014
What Data?

Data on Health and Well-being of American Indians, Alaska Natives, And Other Native Americans

Data Catalog
Contract No. 233-02-0087

Prepared for:
U.S. Department of Health and Human Services
Office of the Assistant Secretary for Planning and Evaluation
Office of Human Services Policy
200 Independence Avenue, S.W.
Washington, D.C. 20201

Prepared by:
Westat
1650 Research Boulevard
Rockville, MD 20850

December 2006

5. Listing of Data Sources

A Picture of Subsidized Households (1998)
Adoption and Foster Care Analysis and Reporting System (AFCARS)
American Community Survey (ACS)
American Housing Survey: Metropolitan Surveys
Annual Survey of Jails (ASJ)
Behavioral Risk Factor Surveillance System (BRFSS)
CAHPS Health Plan Survey Response Data
California Health Interview Survey (CHIS)
Census 2000
Census 2000 - The American Indian and Alaska Native Summary File
Census of Agriculture (2002)
Census of Jails
Census of Tribal Justice Agencies in Indian Country (2002)
Consumer Expenditure Surveys (CE) Interview and Diary Surveys
Current Population Survey (CPS)
Early Childhood Longitudinal Study, Birth Cohort (ECLS-B)
Early Childhood Longitudinal Study, Kindergarten Class of 1998-99 (ECLS-K)
Food Stamp Quality Control Database (FSPQC)
Hawaii Health Survey (HHS)
Head Start Program Information Report
Health and Retirement Study (HRS)
Health Behavior in School-aged Children (HBSC)
Health Information National Trends Survey (HINTS)
Integrated Postsecondary Education Data System (IPEDS)
Medicaid Analytic Extract (MAX)
Medical Expenditure Panel Survey (MEPS)
Medicare Denominator File
Medicare Utilization – Standard Analytic Files (SAFs)
National Aging Program Information Systems (NAPIS) State Program Reports
National Ambulatory Medical Care Survey (NAMCS)
National Assessment of Adult Literacy (NAAL)
National Child Abuse and Neglect Data System (NCANDS)
National Crime Victimization Survey (NCVS)
National Epidemiologic Survey on Alcohol and Related Conditions (NESARC)
National Health Interview Survey (NHIS)
National Hospital Ambulatory Medical Care Survey (NHAMCS)
National Household Education Surveys Program (NHES)
National Household Travel Survey (NHTS)
National Indian Education Study (NIES)
National Longitudinal Mortality Study (NLMS)
National Mortality Followback Survey (NMFS)
National Survey of America’s Families (NSAF)
National Survey of Child and Adolescent Well-being (NSCAW)
National Survey of Family Growth (NSFG)
National Survey of Veterans (NSV)
National Survey on Drug Use and Health (NSDUH)
National Vital Statistics System: Mortality (NVSS-M)
National Vital Statistics System: Natality (NVSS-N)
Panel Study of Income Dynamics (PSID)
Pediatric Nutrition Surveillance System (PedNSS)
Pregnancy Nutrition Surveillance System (PNSS)
Pregnancy Risk Assessment Monitoring System (PRAMS)
Resource and Patient Management System (RPMS)
Runaway and Homeless Youth Management Information System (RHYMIS)
Small Area Income and Poverty Estimates (SAIPE)
Surveillance, Epidemiology, and End Results (SEER)
Survey of Jails in Indian Country (SJIC)
Survey of Program Dynamics
Temporary Assistance for Needy Families (TANF) and Tribal TANF
Tobacco Use Supplement to the Current Population Survey (TUS-CPS)
Treatment Episode Data Set (TEDS)
Uniform Crime Reports (UCR)
United States Renal Data System (USRDS)

Sponsor: U.S. Department of Health and Human Services (DHHS) National Institutes of Health (NIH)/National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Description: The United States Renal Data System (USRDS) is a national data system that collects, analyzes, and distributes information about end-stage renal disease (ESRD) and chronic kidney disease (CKD) in the United States. The USRDS is funded directly by NIDDK in collaboration with the Centers for Medicare & Medicaid Services (CMS). The United Network for Organ Sharing (UNOS) is also providing transplant and wait-list data, under the inter-agency agreement, to this data collection effort in order to improve the accuracy of ESRD patient information.

Relevant Policy Issues: Measurement of Health Status and Disease-specific Measurements.

Data Type(s): Registry

Unit of Analysis: Individual

Identification of AI/AN/NA: Native American (includes American Indians and Alaska Natives.) The combined category Asian/Pacific Islander is used in USRDS reports.

AI/AN/NA Population in Data Set: The population size by race is available in Reference Section M of the 2005 USRDS Annual Data Report (ADR). ESRD incidence and prevalence rates by year for Native Americans (NA) are available in Reference Sections A and B. For example, the incident count and adjusted incident rate per million population for NA in 2003 was 1,097 and 503.9 respectively.

Geographic Scope: The geographic scope of the study is national. Further geographic analysis is possible by state, county, zipcode, and HSA (CDC Health Service Area).

Date or Frequency: Data have been compiled annually since 1988, with the 2004 data being the most recently available for analysis.

Data Collection Methodology: Data for the USRDS Database are compiled from existing data sources including the Centers for Medicare and Medicaid Services (CMS) Renal Management Information System (REMIS), CMS claims data, Facility survey data, CDC survey data, Standard Information Management System (SIMS), Medicare Evidence Form (CMS-2728), ESRD Death Notification Form (CMS-2746), and UNOS transplant and wait-list data. The CMS data files are supplemented by CMS with enrollment, payer history, and other administrative data to provide utilization and demographic information on ESRD patients.

Participation: Mandatory
How Data?

• What’s the denominator? Indigenous Identification?
• What’s the ideal geographic boundary?
• Are tribal-level data available and needed?
• What comparisons are appropriate?
• Who may already be working to link/host data?
• Are secondary analyses priorities?
• What kinds of reporting considerations are important to plan for ahead of time?
Why Data?

• Clear Rationale for the Community & Field

• Awareness about National and International Data Dynamics & Trends

• Defined Outcomes & Goals
Why Data?

Improving Estimates of Indigenous Under-Identification in Key Data Sets

- The Indigenous Identification in Hospital Separations Data Quality Report
- An Enhanced Mortality Database for Estimating Indigenous Life Expectancy: A Feasibility Study
- A Comparative Analysis of Indirect Methodologies for Estimating Indigenous Life Expectancy
- Comparative Life Expectancy of Indigenous People in the Australia, New Zealand, Canada and the United States: Conceptual, Methodological and Data Issues

Guidelines for Data Linkage Activities Relating to Aboriginal and Torres Strait Islander People

- National Best Practice Guidelines for Data Linkage Activities Relating to Aboriginal and Torres Strait Islander People
- Report on the use of linked data relating to Aboriginal and Torres Strait Islander people
- Thematic list of projects using linked data relating to Aboriginal and Torres Strait Islander people

http://www.ncai.org/policy-research-center/initiatives/data-quality
Policy Analysis for Diabetes Research and a Survey of the National Policy Landscape

Timothy D. McBride, PhD.
Data & Policy Institute
University of Colorado, Denver
July 23, 2014
Goals for Talk

- Models, Methods for policy analysis
  - Policy Drivers for Diabetes
- Data, methods
  - Doing policy analytic work: finding policy-related variables
- Looking for policy analysis in unexpected places
  - Policy analysis from analysis of interventions
  - Translation of research to policy
  - Frontiers of policy analysis work
- Funding
- Q&A
Background
Policy Analysis: Problem-Solution Framework

- Problem analysis
  - What is the problem?
  - Understanding the problem
  - Goals and constraints
- Solution analysis
  - Policy alternatives
  - Evaluation and analysis
- Conclusions and recommendations?
  - [Note: this is just one framework I favor. Other frameworks possible…]
Policy Analysis: Policy Process

- The Problem
- Policy Alternatives
- The Politics

Evidence-Based Information & Analysis

Big Policy Drivers

- **Federal**
  - Indian Health Service (HIS)
  - Federal agencies (HHS, NIH, CDC, HRSA, etc.)
  - Congress, Administration
  - Big federal policy changes (e.g., Affordable Care Act)

- **State**
  - Health, aging departments, Medicaid, social service

- **Local/Tribal**
  - Counties/IHS
  - Includes school districts

- **Private sector/employer**
  - Bigger and bigger role given growing role of private plans in Medicare, Medicaid, ACA
Health Insurance Marketplaces:
- Access to affordable coverage for uninsured and small businesses
- Exchange offers access to Private insurance plans
  - Companies offer five types of plans: platinum, gold, silver, bronze
  - Also catastrophic (only available to those under age 30)
- Federally-facilitated (n=34) and State-based marketplaces (n=17)
- Plans offered in rating areas (n=501)

Subsidies:
- Provide assistance to make insurance affordable (up to 400% of poverty line)
- Pegged to second-lowest cost silver plan

Insurance Reforms:
- Eliminate pre-existing conditions, exclusions, rescissions, denials of coverage

Public Program Expansions:
- Strengthen and Expand Medicaid (up to 133% of poverty line)
- NOTE: due to Supreme Court decision, Medicaid Expansion is voluntary (27 expanding Medicaid, 24 not expanding Medicaid)

Mandates:
- Individual and Employer Responsibility
### Enrollment in Affordable Care Act Marketplaces and Medicaid

(October 2013-end of April 2014)

By Type of Marketplace (Federal or State) And Medicaid decision

<table>
<thead>
<tr>
<th>Type of Marketplace</th>
<th>TOTAL</th>
<th>Marketplace Plans (millions)</th>
<th>Medicaid (millions)</th>
<th>Average population density</th>
</tr>
</thead>
<tbody>
<tr>
<td>State-based Marketplaces</td>
<td>7.4</td>
<td>2.6</td>
<td>4.8</td>
<td>246</td>
</tr>
<tr>
<td>FFM/Medicaid-Yes</td>
<td>2.3</td>
<td>1.4</td>
<td>0.9</td>
<td>326</td>
</tr>
<tr>
<td>FFM/Medicaid-No</td>
<td>5.4</td>
<td>4.3</td>
<td>1.1</td>
<td>158</td>
</tr>
<tr>
<td>TOTAL</td>
<td>14.7</td>
<td>8.0</td>
<td>6.7</td>
<td>248</td>
</tr>
</tbody>
</table>

## Enrollment in ACA Marketplaces
(by race and ethnicity)

### Appendix Table C1.
Distribution of FFM Marketplace Plan Selections by Race and Ethnicity
10-1-2013 to 3-31-2014, Including Additional SEP Activity through 4-19-14

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Total Who Selected a Marketplace Plan Including Unknown/Other (A)</th>
<th>Total Who Selected a Marketplace Plan Where Race/Ethnicity Is Reported, Excluding Unknown/Other (B)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Unknown/Other</td>
<td>1,691,170</td>
<td>31.1%</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>13,061</td>
<td>0.2%</td>
</tr>
<tr>
<td>Asian</td>
<td>298,515</td>
<td>5.5%</td>
</tr>
<tr>
<td>Native Hawaiian/Pacific Islander</td>
<td>3,282</td>
<td>0.1%</td>
</tr>
<tr>
<td>African-American</td>
<td>625,934</td>
<td>11.5%</td>
</tr>
<tr>
<td>Latino</td>
<td>403,632</td>
<td>7.4%</td>
</tr>
<tr>
<td>White</td>
<td>2,360,672</td>
<td>43.3%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>49,912</td>
<td>0.9%</td>
</tr>
<tr>
<td>FFM TOTAL</td>
<td>5,446,178</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

### Uninsured prior to passage of ACA (2012)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percent of Uninsured</th>
<th>Uninsured rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>AI/AN</td>
<td>1.5%</td>
<td>16.3%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>4.5%</td>
<td>25.6%</td>
</tr>
<tr>
<td>African-American</td>
<td>14.2%</td>
<td>20.6%</td>
</tr>
<tr>
<td>Latino</td>
<td>38.2%</td>
<td>30.7%</td>
</tr>
<tr>
<td>White</td>
<td>38.8%</td>
<td>13.3%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>2.8%</td>
<td>13.6%</td>
</tr>
</tbody>
</table>

**NOTE:** Marketplaces only, does not include Medicaid

Medicaid/CHIP coverage growth just as large as Marketplaces, and more low income
ACA includes multiple opportunities to analyze effects of exogenous policy change on chronic disease

- Starting with population with chronic disease (such as diabetes) or at risk for chronic disease, and uninsured
- If some of them obtain insurance coverage through ACA (and some do not), what is the effect of increased access to insurance coverage on many variables of interest
  - Health status (e.g., HbA1C, BMI, etc.)
  - Health utilization (e.g., drug use, physician visits)
  - Medical care costs
- How does this compare for those who obtained coverage or not? In states that expanded Medicaid coverage or not?
Other big national policy drivers

- ACA may be part of major trends in national health care landscape change
- Major trends in health sector, health policy
  - Slowing growth in health spending
  - Health sector leading growth in employment
  - Private sector changing: a perfect storm?
    - Hospitals: slow growth, layoffs
    - Growth of managed care
    - Accountable care organizations
    - Pay for performance/quality
  - Demographic transition (aging of U.S.)
  - Growth in minority populations (focus on disparities)

Exhibit 1. Year-Over-Year Growth Rates in Health Spending

Source: Altarum monthly national health spending estimates
Compares monthly health spending to the same month from the previous year
Types of Policy Analyses

- Quantitative
- Qualitative
- Political analyses
Policy analysis of Outcomes (traditional HSR)

- Hypothesis: what affects diabetes outcomes at individual level of policy change? (or sometimes at more aggregated level (e.g., tribal, county, state)
- What is a policy change? More on that in a moment
- Variables to consider:
  - Outcome variable: Diabetes/health outcomes
  - Policy variables (more on that in a moment)
  - Economics/Cost/Effectiveness
  - Politics/Process
- Approaches
  - Pre/post policy intervention
    - For example:
      - Before and after 2014, before and after passage of ACA
      - Cross-sectional (compare places where intervention occurred to where it did not)
    - For example: comparison of places where Medicaid coverage was expanded and where it was not
Policy Evaluation

- Hypothesis: what affects diabetes outcomes at individual level of a diabetes program? (often grant-funded)
- Can this be a policy analysis?
  - Two key points:
    1. Policymakers often initiate these programs
    2. Even if program was designed to test whether an intervention worked, it can lead to recommendations for policymakers
    3. What is a policy change? More on that in a moment
- Variables to consider:
  - Outcomes: as above, diabetes/health outcomes
  - Right hand side:
    - Intervention: treatment/control
    - Economics/Cost
Policy analysis: Key Point

- Key points:
  - LHS is outcome variable of interest
  - RHS includes policy variable or variables (as well as control variables)
- Parallel to clinical trial?
  - Focus: is change in policy variable associated with change in outcome of interest?
Policy Variables

- Sometimes in the data set, sometimes not in the data set
- Could be:
  - Change in access to services
  - Insurance coverage of diabetes (change in “price” of services)
  - Access to care
  - Regulations (e.g., bans; removing unhealthy foods from vending machines)
  - Marketing (e.g., encourage healthy habits)
- If not in the data set, need to find the data and add it to existing data
  - Match on variables such as location (state, county)
  - Match on other individual level variables
- Sources of data: many existing public sources
Finding Policy Analyses

- Affordable Care Act (ACA)
- Looking for Policy Results in Unexpected Places
  - Exogenous policy changes
  - Clinical or Project Outcomes leading to Policy Recommendations
  - Extending finalized Work into Policy Implications
  - Simulations
Translation of research to policymakers
- Working with national, state, local, tribal policymakers
- What methods work?
In Knowledge translation process, what are the best methods for translating and delivering evidence-based research to policy? Through guidelines (T2) to improve population health (T4)?

**FIGURE 1—Knowledge integration process.**
• Policy making not always rational
  • Rational decision making: research-based, pragmatic, and largely context free
  • Policy makers influenced by budget, ideology, interest groups, other policy makers)
• Culture clash between Policymakers and researchers
  • Policymakers’ view of researchers
    • They take forever; often late with the results.
    • What is this stuff they write? Who can understand it?
    • They’re always hedging. I can’t get a straight answer.
    • They don’t answer the question I thought I asked.
    • They take little responsibility for the implications of their findings.
  • Researchers’ view of policymakers
    • They don’t ask researchable questions.
    • They don’t accept uncertainty.
    • They don’t appreciate the influence of publish or perish on my life.
    • They want unrealistic turn-around for results.
    • They expect me to drop everything and delivery results for policy input.
    • They want “bottom line” answers to take them off the policy hook.
    • They can’t be trusted with my results—misinterpret/misuse

Source: Williams C. Director Office of Health Information, AHRQ. Presentation to 2000 Summer Institute for Professional Health Legislative Staff Development. UNC.
With this Culture Clash, How Can Researchers Affect Policy?

- Researchers need to
  - understand the policy making process
  - design policy-relevant research
  - be aware of policy time constraints
  - disseminate research findings in language and mediums that policy makers will understand
  - become directly involved in the policy making process or can work with advocates

Tailor the design of products

- Different products for different stakeholder groups.
- Policy makers prefer short, user-friendly products
  - Policy briefs or summary fact sheets with key descriptive findings
  - However, journal articles remain important reinforcing the credibility of the research.
- Use Policy briefs or other dissemination products
  - Briefs, briefings
  - Website, webinars

Simulation analysis
- Use multivariate or other analyses and build models of behavior
- Simulation models excellent for estimating results beyond what was found in actual sample, or predicting effects of new policy change (e.g., ACA)
- Simulation models drove analysis of ACA (including my model)
- My view: simulations can be done with many papers that include multivariate analyses

Behavioral economics
- Changing public or private policies to change individual behaviors
- For example:
  - Local insurance company offers debit cards and puts money on the cards if individuals engage in healthy behaviors
  - Cell phones to push messages for healthy behaviors to individuals

Private/public sector collaborations
- Wellness programs
- All-payer approaches
<table>
<thead>
<tr>
<th>Grant #</th>
<th>Description</th>
</tr>
</thead>
</table>
| PAR-13-365 | Evaluating Natural Experiments in Healthcare to Improve Diabetes Prevention and Treatment (R18)  
To support research to evaluate large scale policies or programs related to healthcare delivery that are expected to influence diabetes...The goal is to support research that meaningfully informs clinical practice and health policy related to prevention or management of diabetes. |
| PAR-12-257 | Time-Sensitive Obesity Policy and Program Evaluation (R01)  
This FOA is intended to encourage and support research in which a unique and time sensitive opportunity has arisen to collect baseline data and then prospectively assess effectiveness of an imminent policy or program designed to prevent or reduce obesity in a given population. Policy is broadly defined to include both formal public policies at local, state and federal levels of government, as well as organizational level policies, such as those implemented by organizations, schools or worksites. Program is defined as a set of activities initiated by governmental or other organizational bodies to enhance obesity prevention and control. |
Conclusions
Conclusions

- Role of Policy in Diabetes research work often overlooked
- Many major changes happening at the federal, state, local, tribal levels that create key opportunities for diabetes translation research
- Agencies, funders keenly interested in policy-relevant and policy-related diabetes translation work
Questions, Discussion?

- Contact Information
  - Timothy McBride, PhD
    - Washington University, Brown School
    - tmcbride@wustl.edu

- Questions??