Reconsidering “Shaping a Health Statistics Vision for the 21st Century”

National Committee on Vital and Health Statistics
26 February 2009

Daniel J. Friedman, PhD
Population and Public Health Information Services

R. Gibson Parrish, MD
Dartmouth Medical School
Topics

Shaping a Health Statistics Vision for the 21st Century (NCVHS, 2002)
- Process
- Definitions
- Conceptual frameworks
- Findings
- Principles
- Recommendations

Reconsidering Shaping a Health Statistics Vision for the 21st Century
- Purpose
- Process
- Products and timeframe

NCVHS ratings of recommendations
Partners

- National Committee on Vital and Health Statistics
- National Center for Health Statistics
- DHHS Data Council
Joint NCVHS, NCHS, and DHHS Data Council process for developing the 21st century for health statistics

- Association for Health Services Research
- National Conference On Health Statistics
- NAPHSIS Annual Meeting
- Launching Healthy People 2010
- NCVHS 50TH Anniversary Symposium
- CDC Assessment Initiative Annual Meeting
- CDC Executive Leadership
- AMCHP Annual Meeting
- DHHS Data Council
- WHO Collaborating Centres for the Classification of Diseases

Workshop Summary

National Academy of Sciences Workshop, 1999

Commissioned Papers

Local Discussion Groups, 1999-2000:

Expert Discussion Groups, 1999:

Shaping a vision for 21st century health statistics, June 2000 interim report

Regional Public Hearings, 2000-2001:

Solicitation of Recommendations from Vision Process Participants 2001


NCVHS Recommendations for Implementing the vision 2002
Defining Health Statistics

Numerical data that characterize the health of a population and the influences and actions that affect the health of a population
The Health Statistics Enterprise

... is the infrastructure and activities necessary to produce health statistics.

The Mission of the Health Statistics Enterprise

... is to efficiently provide timely, accurate, and relevant information that can be used to improve the nation’s health.
The Health Statistics Enterprise

- Collects, analyzes, and disseminates data on the health of populations and the factors that influence health
- Includes public and private organizations and individuals at all geopolitical levels that perform the processes of health statistics
- Is highly decentralized
Conceptual Framework: Influences on a Population’s Health

...helps to maintain a focus on needed data and guides the health statistics enterprise.

- Focuses on communities and their context
- Delineates major influences on health
- Emphasizes the level and distribution of health
- Defines a research agenda for improving a population’s health
Influences on a Population’s Health
Influences on a Population’s Health
Unrealized Potential: Causes

- Narrow definition of population health
- Focus on individual rather than community
- Limited vertical and horizontal integration of data
  - State and local
  - Vulnerable populations
- Insufficient longitudinal and life cycle data
- Disparity between data availability and data use
Unrealized Potential: Results

Abundant data, too little information

– Cultural and political contexts
– Community attributes
– Appropriate measures of health
  ▪ Individual disease?
  ▪ Life cycle?
  ▪ Functional status?
  ▪ Well-being?
– Geographic and subpopulation detail
Conceptual Framework: Health Statistics Cycle

...helps to maintain a focus on needed components of a rational health statistics process

- Focuses on defining user data needs, identifying data sources, translating data into useful statistics for users, and evaluating the extent to which user needs are met
- Central role of integrating hub
Health Statistics Cycle

Defining data needs and analytic approaches
- Policy needs
- Research and hypothesis testing needs
- Program needs
- Monitoring and accountability needs

Evaluating extent to which needs are met
- Extent to which statistics meet analytic objectives
- Extent to which attributes of data enable user needs to be met
- Accessibility of statistics for users

Specifying necessary data attributes
- Target population
- Substantive detail
- Time
- Quality

Translating statistics for users
- Appropriateness for meeting content-driven needs
- Accessibility for data users
- Role of NHII

Identifying appropriate data sources
- Data already in form useful for analysis
- Data to be extracted from existing data systems
- Data available through modifications to existing data systems
- New data collection
- Data accessible through the NHII

Integrating hub
- Coordination
- Stimulating collaborative efforts
- Standards setting
- Resetting vision
- Generating new methods and approaches
- Privacy, confidentiality, security

Analyzing statistics

Collecting, aggregating, and compiling data
- Collecting data through surveys
- Accessing data through the NHII
- Processing existing data into analytic files
- Packaging data in accessible, useful formats
Unrealized Potential

Existing enterprise-wide coordinating and integrating efforts largely ineffective
– Insufficient
  – Connections between data sources, data collectors, and data users
  – Attention to developing consensus approaches and standards to simplify collection, protection, and access
  – Resources
    – investment in new methods
    – training
      » producers
      » Users
    – places at risk performance and usefulness of data collection systems
  – Collaboration with decision-makers
– Lacks
  – Overall confidentiality and data-sharing framework
  – Flexibility and adaptability
  – Enterprise-wide planning forum
– Undue burden on data sources
Vision for Health Statistics Enterprise: Ten Guiding Principles

1. Enterprise-wide planning and coordination
2. Broad collaboration among data users, producers, and suppliers at local, state, and national levels
3. Rigorous policies and procedures for protecting privacy, confidentiality, and security
4. Flexibility to identify and address emergent health issues and needs
5. Use of data standards
Vision for Health Statistics Enterprise: Ten Guiding Principles

6. Sufficient detail at different levels of aggregation
7. Integrated, streamlined data collection for multiple purposes
8. Timely production of valid and reliable health statistics
9. Appropriate access to and ease of use of health statistics
10. Continuous evaluation of the completeness, accuracy, and timeliness of health statistics and the ability of the health statistics enterprise to support their production
NCVHS Recommendations

Developing the recommendations

- Suggestions throughout vision process
- Iterative process with vision participants
  - Recommendations solicited during regional public hearings
  - Structured solicitation of recommendations
  - Draft recommendations circulated
  - Revised draft of recommendations circulated
NCVHS Recommendations

Overview of recommendations

- Detailed recommendations for achieving the ten guiding principles (30 recommendations)
- Recommendations for moving toward adoption of the overarching conceptual framework (6 recommendations)
- Recommendations relate to:
  - Health statistics enterprise structure
  - Data set development
  - Data standards
  - Privacy policy
  - Data access and use
  - Training
  - Evaluation
  - Research agenda
Purpose--Reconsidering “Shaping a Health Statistics Vision”

- Assess progress on Vision recommendations
- Update, reconsider, and revise Vision in light of national and international developments
  - Models of population health and new research on influences on population health
  - Ubiquitous presence of the World Wide Web
  - Standards for EHRs and PHRs
  - NCVHS and other reports
  - Impacts on organization of health statistics in 2010’s
Process--Reconsidering “Shaping a Health Statistics Vision”

- Literature review
  - “Shaping a Health Statistics Vision”
  - “Information for Health”
  - Other relevant NCVHS, NCHS, Markle Foundation, Commonwealth Fund, RWJF, NAS, and other reports, Web sites, and grey literature
  - International developments in health statistics

- Expert interviews

- Iterative reviews of findings with NCVHS and NCVHS staff
## Products and Timeframe--Reconsidering “Shaping a Health Statistics Vision”

<table>
<thead>
<tr>
<th>Task</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suggestions on updates to “Vision”</td>
<td>May 2009</td>
</tr>
<tr>
<td>Assess progress since 2002 on <em>Vision</em> recommendations</td>
<td>June 2009</td>
</tr>
<tr>
<td>Discuss with NCVHS possible changes to <em>Vision</em></td>
<td></td>
</tr>
<tr>
<td>Draft working paper on expected changes to “Vision”</td>
<td>September 2009</td>
</tr>
<tr>
<td>Recommendations on future workshops or public hearings</td>
<td>September 2009</td>
</tr>
</tbody>
</table>
NCVHS Ratings of Recommendations

- Considerations
  - Current relevance
  - Intersection with e-health
  - Long-term importance

- Summary judgment
  - High
  - Medium
  - Low
Dan Friedman
danieljfriedman@verizon.net
617.797.6710

Gib Parrish
gib.parrish@gmail.com
802.592.3358