Community Health Data, Data Stewardship and Data Access and Use: Tools and Resources

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Speakers

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“NCVHS Role and Contributions in HHS Health Data Policy”

“The Community as a Learning System for Health: Using Data to Improve Local Health
“A Stewardship Framework for the Use of Community Health Data”

“Guidance on Increasing Usability and Accessibility of Federal Health Data”

“Improving Health Data Access and Use”
NCVHS Role and Contributions in HHS Health Data Policy
HHS Data Policy

- HHS Mission relies on data
- HHS Strategic Plan 2014-2018
- HHS Data Council and HHS Division of Data Policy
- NCVHS – federal advisory committee
- NCHS – designated health statistics agency; specialized agency surveys and administrative data
- HHS wide Survey Planning, Data Standards, Open Data and HHS Data Collection Portfolio Management
- HHS Data Collection Strategy
  http://aspe.hhs.gov/datacncl/DataStrategy/index.cfm

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of the Assistant Secretary for Planning and Evaluation
The National Committee on Vital and Health Statistics

- One of the oldest statutory public federal advisory bodies to the HHS Secretary
- Focuses on health data and statistics, standards, and health information policy
- Provides advice and assistance to various HHS groups and agencies (HHS Data Council, CMS, CDC, HRSA, AHRQ, others)
- Serves as a forum for interaction with private and public sector groups on a variety of health data and information issues
# NCVHS Milestones

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1949</td>
<td>Established as federal advisory committee</td>
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<td>1974</td>
<td>Public Health Services Act gave NCVHS official status as statutory public advisory committee to the Secretary of HEW (now HHS)</td>
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<td>1996</td>
<td>HIPAA charged NCVHS with advising Secretary on health data standards and privacy policy</td>
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<td>2003</td>
<td>Medicare Modernization Act charged NCVHS with recommending standards for electronic prescribing</td>
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<td>2010</td>
<td>Affordable Care Act charged NCVHS with advising the Secretary on Operating Rules for HIPAA Administrative Simplification</td>
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<td>2014</td>
<td>NCVHS designated as the Review Committee (under ACA provisions), to review status of adoption/implementation of standards/operating rules, and advise on changes needed</td>
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NCVHS Configuration

• 18 members appointed for four year terms
• Organized around four core areas:
  • Standards (including HIPAA administrative transactions, code sets, identifiers)
  • Population Health
  • Privacy, Confidentiality and Security
  • Data Access and Use
• Holds quarterly meetings, convenes public hearings, listening sessions, workshops, roundtables
• Develops and delivers practical, timely, thorough recommendations to the Secretary
• Provides periodic reports to Congress
• Releases reports and resources to the industry
## NCVHS Domains

<table>
<thead>
<tr>
<th>Areas</th>
<th>Focus</th>
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<tr>
<td>Standards</td>
<td>Standards, code sets, identifiers, operating rules for HIPAA transactions, as required under HIPAA, MMA, and ACA; public health informatics standards</td>
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<tr>
<td>Population Health</td>
<td>Vital and health statistics policy; population-based data to enable communities to identify disparities and become learning systems for health</td>
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<tr>
<td>Privacy, Confidentiality and Security</td>
<td>Emerging issues related to health information privacy, confidentiality and security and data stewardship</td>
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<tr>
<td>Data Access and Use</td>
<td>Principles, best practices, guidelines, gaps on the availability, accessibility, use, utility, usability, and usefulness of HHS data resources</td>
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NCVHS Recent Notable Contributions

Visioning Documents

  ▪ Emphasized role of all factors influencing health
• National Health Information Infrastructure (2002)
  ▪ Led to the creation of Office of the National Coordinator for Health Information Technology
• Towards Enhanced Information Capabilities for Health (2010)
  ▪ Concept paper highlighting availability, accessibility, standardization and privacy and security of health information

Population Health

• Community as a Learning Health System Framework (2011)
• Supporting Community Data Engagement – NCVHS Roundtable (2014)
• Electronic Standards for Public Health Information (2014)
Administrative Simplification

- Fifteen years of oversight/advice on adoption/implementation of standards, code sets, identifiers, operating rules to fulfill HIPAA and ACA administrative simplification provisions
- HIPAA Reports to Congress (2011 - 2014)

Privacy and Security

- Privacy and Security of Personal Health Records (2009)
- National Stewardship Framework for Health Information Privacy (2009)
- Stewardship Framework for the Use of Community Health Data (2012)

Data Access and Use

- Steps to improve Usability, Use and Usefulness of HHS Data Resources (2014)

Context

Natural environment
- Air quality
- Water quality
- Climate and weather
- Topography and soil
- Environmental contaminants
- Animals and plants

Cultural context
- Norms and values
- Religion
- Racism and sexism
- Discrimination
- Competition/cooperation

Political context
- Public policies and Laws
- Social
- Economic
- Health
- Environment
- Political culture
- Differential political
- Enfranchisement or participation

Health services
- Structure
  - Numbers of personnel
  - Types of personnel
  - Organization
  - Facilities
  - Types of services
  - Accessibility
  - Process
  - Professional behaviors
  - Utilization
  - Treatment modalities
  - Cost and financing
  - Access and Use
  - Quality

Built environment
- Housing
- Workplace
- School
- Transportation
- Communication
- Access

Biological characteristics
- Community age distribution
- Community gender distribution
- Genetic make-up

Social attributes
- Cohesion
- Influence
- Networks
- Support
- Social change

Economic resources
- Employment
- Control over work
- Income
- Income inequality
- Economic change
- Education
- Child care
- Early childhood experience
- and education

The population’s health

Level

Disease

Functional status

Well-being

Population-based health programs
- Water Supply
- Waste Disposal
- Air Pollution Control
- Public Health Programs
- Children
- Adults

Collective lifestyles and health practices
- Diet
- Wellness behavior
- Physical activity
- Sexual practices
- Smoking
- Substance abuse
- Violent behavior
- Access to health information
NCVHS Website and Resources

- www.ncvhs.hhs.gov
- All meeting announcements, letters to the Secretary, reports, tools, and other resources available from this site
- Electronic/remote access to meetings and meeting materials
Walter G. Suarez, MD, MPH

The Community as a Learning System for Health: Using Data to Improve Local Health
Health is a Community Affair

“Getting data into the hands of communities and ensuring they have tools and capacities to use them could move the nation toward realizing the public benefits of the informatics revolution.”

The Community as a Learning System for Health, NCVHS, December 2011, p. 7
Impetus for Focus on Community Health Data

**Community**: an interdependent group of people who share a set of characteristics and are joined over time by a sense that what happens to one member affects many or all of the others.

- **Upsurge in community health Initiatives**
- **Learning Health System project**

How communities can become learning systems for health and what resources exist and are needed to help them?
The Community as a Learning System: Using Local Data To Improve Local Health

A Report of the National Committee on Vital Health Statistics
NCVHS Roundtable on Supporting Community Data Engagement, October 2014

Purpose: To bring together community leaders, health data connectors, and health data suppliers

• to identify major lessons, needs and gaps in local data access and use, and
• to explore how HHS can better support local data efforts.
Participants included

- **Communities:** Sonoma County CA, Louisiana PH Institute, Douglas County NE, Seattle

- **Connectors:** Community Commons, Healthy Communities Institute, County Health Rankings & Roadmaps, NAHDO, ASTHO, NQF, Kaiser Permanente, Catholic Health Assn., PHAB

- **Data Suppliers:** NCHS, SAMHSA, CMS, AHRQ, Healthy People 2020, VHA, ASPE

- **Philanthropy:** RWJF (Culture of Health Initiative)

- **NCVHS** (*full Committee and/or Working Group*): 12 members plus staff
Major findings:

• Communities vary considerably in the amount and types of assistance they need to bring about data-based improvements in local health.

• To inform local projects, data and information should correspond to authentic boundaries, have relevant granularity, and be actionable.

• Communities need assistance with data stewardship to help them protect residents’ privacy and confidentiality and optimize data quality.

• A growing number of intermediary organizations provide Web-based resources to facilitate local action.

• The federal government should support community-driven change.

http://www.ncvhs.hhs.gov/130430sm.pdf
The most striking Roundtable theme concerned the expanding drive for health equity within communities and its implications for data access and use. The emphasis on equity is ... about the nature of community health and how to improve it ... how to operationalize the concept of the social determinants of health. There are critical local data gaps, especially with regard to health care access, inequality in health outcomes, costs and affordability, care coordination, and determinants of health specific to each community.
Letter to the Secretary: Recommendations

- Create a virtual Federal “home” for community-facing data work; establish an interagency Community Health Data Coordinating Committee
- Develop and publish an HHS Strategic Community Health Data Plan
- Expand opportunities for ongoing input into relevant Federal health data policy from knowledgeable community representatives
- Expand high-level collaboration and coordination with other Federal departments that operate or fund community-level data and data-relevant programs
Letter to the Secretary: Recommendations (cont.)

- Create a mechanism for high-level coordination and collaboration between HHS and non-governmental organizations to support and inform community data engagement
- Develop resources to help communities find, select, and use appropriate data tools
- Where possible, and preferably through a regional system that builds on existing Federal regional offices, expand on-site technical assistance to help local communities access and use available data and tools
- Using the NCVHS Community Data Stewardship Toolkit, educate community members and leaders on appropriate data stewardship practices for collecting, storing, preserving, disseminating, and publicizing health data
Walter G. Suarez, MD, MPH

A Stewardship Framework for the Use of Community Health Data
What is Data Stewardship?

- The responsibility, guided by principles and practices, to ensure the knowledgeable and appropriate use of data

Why a Toolkit and Why Now?

- Communities asked for practical guidance
- Illustrates principles in NCVHS’s letter to the Secretary on *Stewardship Framework for the Use of Community Health Data* (Dec 5, 2012)
  - *Stewardship Framework* principles and their application defined, explained and illustrated.
  - Applicable laws and regulations cited and explained.
  - Practical tips, checklists and cautions highlighted to avoid missteps and potential harm.
Data Lifecycle

- Effective stewardship extends to all phases of lifecycle
- Community health data can be original data gathered for the purpose or repurposed data
- Use of repurposed data is expanding, driven by technology
7 Principles of Data Stewardship

- Accountability
- Openness, Transparency, and Choice
- Community and Individual Engagement and Participation
- Purpose Specification
- Quality and Integrity
- Security
- De-Identified Data
Accountability

- Accountability may lie with an individual or entity.
- Different people may be accountable for different phases of the data lifecycle or different stewardship elements.
- An accountable individual or entity should be named and held responsible for stewardship.
- Data use agreements (DUAs) are one way to establish accountability ground rules among data users.
Advancing Openness, Transparency and Choice

**Notice** is information provided to the community about data use.

**Consent** is the process of getting permission from a community or individual to use data.
Community and Individual Engagement and Participation

- Evaluate opportunities for engaging communities and individuals at every step in the data lifecycle and across all elements of the stewardship framework.
- Be aware of the concerns of subgroups within communities whose interests may be different from those of the larger community.
- Consider the risk of stigmatization of communities or small groups and engage the community or individuals to determine an action plan for addressing the risk.
Purpose Specification

• Define the purpose of data collection or use of repurposed data
• Consider how to engage the community in purpose specification
• Anticipate possible adverse impacts of data use or collection.
• Be aware that data may later be repurposed, design collection accordingly
• When using repurposed data, consider the need for additional notice or consent
• Address and align goals of collaborating entities regarding goals, funding, use limitations
Quality and Integrity

- Ensure that data quality and integrity are maintained throughout the data lifecycle.
- Before merging data sets, consider how the merger will affect data quality and integrity.
- Example quality questions to ask:
  - Are the populations the same for the different data collection efforts?
  - Do survey questions and response categories match?
  - Might differences in survey administration dates affect survey results?
  - What were the survey sample designs?
Security

**Physical**
- Install locks on cabinets or rooms where paper records are stored
- Keep records away from areas vulnerable to damage in a flood
- Protect electronic storage facilities against break-ins or destruction
- Back up data with off-site storage capabilities

**Technical**
- Maintain logs of system access and unauthorized extraction of data
- Add encryption specific elements in a data set
- Data set as a whole
- Devices that allow access to the data set, such as laptop computers
- Implement monitoring to scan for and identify cyber attacks

**Administrative**
- Run a risk analysis
- Set up policies and procedures for accessing paper records, disposing of data, or adding new equipment on a network
- Train those with access to sensitive information in data security
- Require robust passwords
- Control who has access to view or change the data
- Conduct due diligence on employees who handle data
- Implement an incident response program
De-identified Data

Certain combinations of values may be so rare that they create a “fingerprint” pointing to only one person.
Guidance on Increasing Usability and Accessibility of Federal Health Data

Vickie M. Mays, PhD, MSPH
Why A Working Group On Data Access and Use?

The problem:

• Changes in the data environment: Technology that makes it easier and cheaper to access and manipulate data
• HHS infrastructure in which data stewards have extensive expertise based on more traditional modes of data utility.
• Data access demands by new customers
• Secretary’s commitment as part of ACA to make data more available to guide health and health care

The solution:

• Leverage the NCVHS, created in 1949
• Add a working group of experts who could advise on expanding data access and encouraging innovative use, including content, technology, media, and audiences
Changes In Customers for Federal Survey Data

- Traditional Use By Researchers and Health Systems
- Entrepreneurs/Innovators/Data –Driven Solutions and Warehouses
- Community’s Use of Their Data
- Consumer
Changes in How Data is Accessed and Health Information Is Communicated

- **Traditional**: Reports and Scientific Articles/Computer or Library Search/TV/Newspapers
- **Primary search for health information through smartphones**, attention to Twitter
- Blogs (WebMD), patient listservs, Google, Yahoo
- **Demand for data in real time to respond in real time**
- **Mash up activities to address social determinants and social justice health inequities**
Examples Of User Demands of HHS Data

- How can I find if the same variable (i.e. smoking) across HHS datasets is measuring the same behavior. Is a smoker always a smoker?
- Where can I find data about my neighborhood? How healthy is my community?
- Which therapy has better outcomes?
- Do hospitals with a certain number of beds prefer some EHR vendors over others?
- How many heart attacks are there per year? What is my risk? What can I do to lower my risk?
- What is the biggest health challenge facing a teenage woman? Does that change if she lives in Toledo, OH or Miami, FL?
- Which surgeon has the lowest complications rates for a specific type of surgery?
- Where can I find addresses for every drug treatment centers in America?
- What is the best way to link this dataset with physician names, addresses and education to this other dataset with prescription drug spending?
Concepts For Greater Access and Use of HHS Survey Data

- Accessible
- Findable
- Usable
- Useful
- Comprehensible
- Data Stewardship

- Linking and Combining
- Quality
- Supported by data provider
- Community and learning
Solutions For Greater Access and Use of HHS Survey Data (subset)

- Promoting Usability and Usefulness
  - Metadata
  - API’s
  - Tagging
  - Data Explorers and Visualizations
  - Assessment of data quality and completeness
  - Refresh rates confidence and transparency
- Promoting user-tailored resources and interaction
- Promoting Social Learning and Community
  - Feedback loops
  - Suggestive content and solutions
- Promoting Data Stewardship
Work Group Development of Philosophy/Principles For Data Stewards

• Sustenance: data should have continuing persistence via stewardship (for public use this does not need to be cost draining, cf. public explorers like google, the internet archive, etc.)

• Data releases sooner and less perfect: Release of data can err on the side of being incomplete vs. perfect, with appropriate disclosures

• Enforcement: use mechanism such as a machine readable clause for public data (i.e. all data shall be machine readable, provide basic and appropriate metadata including ERDs and data dictionary, and an indication of forward support
Work Group Development of Philosophy/Principles For Data Stewards

- Detail who your survey serves and seeks ways to expand the customer (user type) base
- Process in place to learn about needs of the audience. Communicate with them directly, early and often...
- Apply what’s learned
- Ability to understand data: context for data, about its original purpose, and limitations and whether other opportunities exist
- Data users need to assess value of complimentary investments so need visibility into how frequently will the data be released/refreshed
Discussing User Needs

Discussion and Q&A
Thank You!

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Key Reports:

• The Community as a Learning Health System: Using Local Data to Improve Local Health -  


• Toolkit for Communities Using Health Data: How to Collect, Use, Protect and Share Data Responsibly -  
What is Data Stewardship?

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