

2015 National Conference on Health Statistics



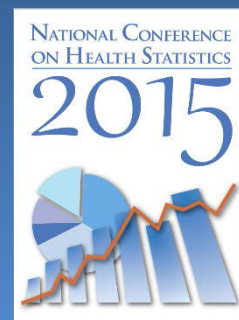
National Committee on Vital and Health Statistics

Advising the Secretary of Health and Human Services
on health information policy since 1949.

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



North Bethesda, MD
August 25, 2015



Speakers

James Scanlon

- NCVHS Executive Staff Director
- Deputy Assistant Secretary, Office of Planning and Evaluation, HHS

“NCVHS Role and Contributions in HHS Health Data Policy”

Walter G. Suarez, MD, MPH

- Chair, NCVHS
- Executive Director, Health IT Strategy and Policy, Kaiser Permanente

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

Vickie M. Mays, PhD, MSPH

- Chair, NCVHS Work Group on Data Access & Use
- Professor and Director, UCLA Department of Psychology & Fielding School of Public Health, Department of Health Policy and Management

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

Kenyon Crowley, MBA, MS

- Member, Work Group on Data Access & Use
- Deputy Director, Center for Health Information and Decision Systems (CHIDS), Robert H. Smith School of Business, University of Maryland

“Improving Health Data Access and Use”

James Scanlon

NCVHS Role and Contributions in HHS Health Data Policy

HHS Data Policy

- HHS Mission relies on data
- HHS Strategic Plan 2014-2018
 - <http://www.hhs.gov/strategic-plan/priorities.html>
- 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/datacnci/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

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



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

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



NCVHS Recent Notable Contributions

Visioning Documents

- 21st Century Vision for Health Statistics report (2000)
 - 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)



NCVHS Recent Notable Contributions (cont.)

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)

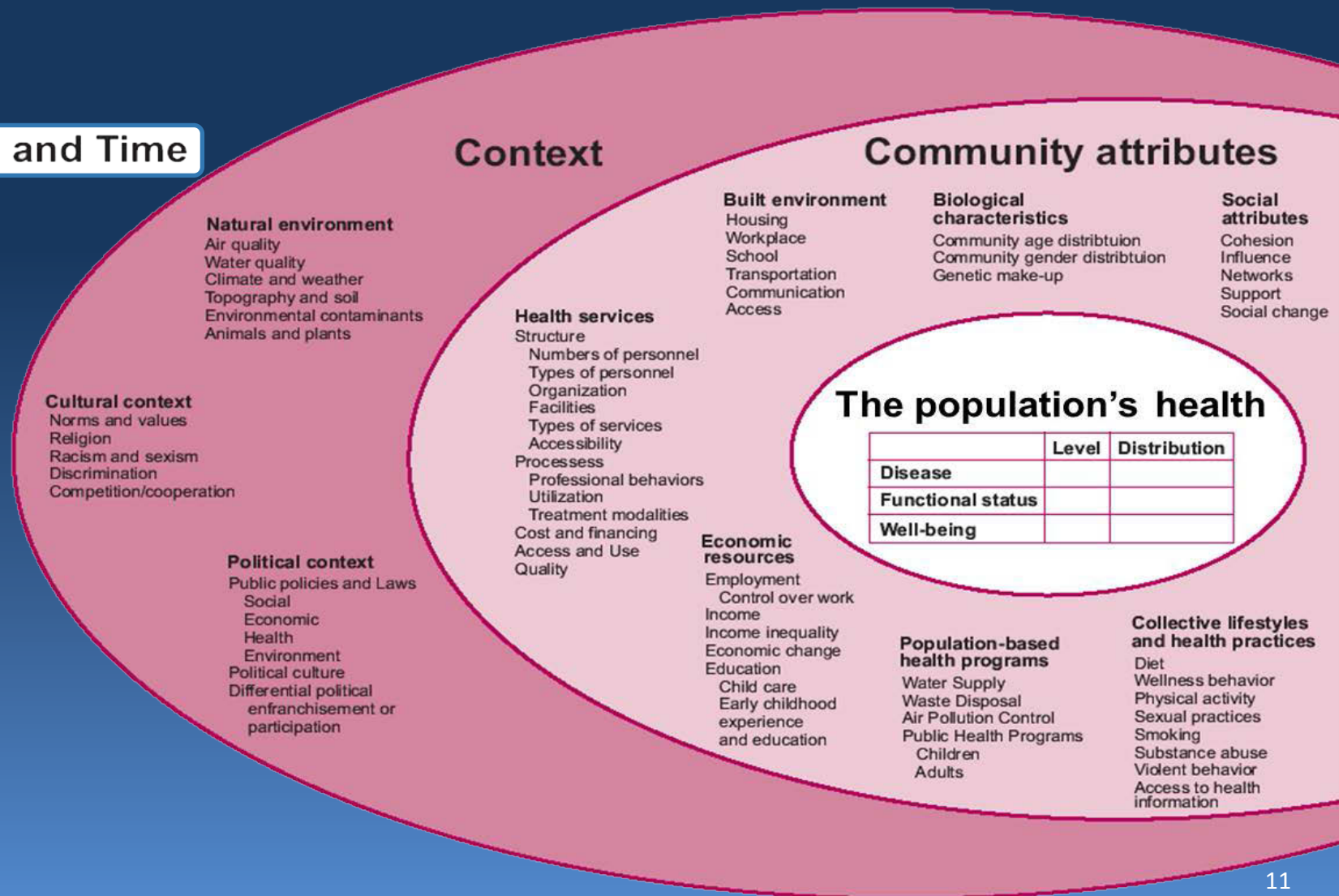
Data Access and Use

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



Shaping a Health Statistics Vision for the 21st Century (2002)

Place and Time



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

The screenshot displays the official website of the National Committee on Vital and Health Statistics (NCVHS). The header features the NCVHS logo, the organization's name, and its mission statement: "Advising the Secretary of Health and Human Services on health information policy since 1949." A Google Custom Search bar is located in the top right corner. The main navigation menu includes links for Home, About, Subcommittees & Work Groups, Membership, Recommendations, Reports & Presentations, Transcripts & Minutes, and Meeting Calendar. A secondary navigation bar lists Community and Population Health, Data Stewardship, Standards, Quality, and Health Data Access and Use. The central content area provides a detailed description of the NCVHS as a statutory public advisory body established in 1949, which provides advice on health data issues related to community and population health, standards, privacy, confidentiality, quality, and data access and use. Below this, the "NCVHS Products" section highlights "Recent Recommendations, Reports and Presentations," featuring a grid of links to various documents such as "Recommendations on supporting community data engagement by increasing alignment..." (dated 06/28/2016) and "Coordination of Benefits, HPID, & ICD-10 Delay..." (dated 08/23/2014). A "Featured Items" section at the bottom showcases additional resources, including "Supporting Community Data Engagement – An NCVHS Roundtable..." (dated 10/28/2014) and "Joint Roundtable on Health Data Needs for Community Driven Change Summary Report..." (dated 06/02/2013). The footer contains the contact information for the National Center for Health Statistics, along with logos and links for HHS.gov, HealthIT.gov, CDC, CMS.gov, and ASPe.hhs.gov/ds/ncvhs/.

National Committee on Vital and Health Statistics
Advising the Secretary of Health and Human Services on health information policy since 1949.

Home About Subcommittees & Work Groups Membership Recommendations, Reports & Presentations Transcripts & Minutes Meeting Calendar

Learn more >

Community and Population Health Data Stewardship Standards Quality Health Data Access and Use

The National Committee on Vital and Health Statistics (NCVHS) is the statutory public advisory body to the Secretary of Health and Human Services on health information policy. Established in 1949, NCVHS provides advice and assistance on key health data issues related to community and population health, standards, privacy and confidentiality, quality, and data access and use. It reports regularly to Congress on HIPAA implementation, and serves as a forum for interaction between HHS and interested private sector groups. Members have distinction in such fields as public health, education, informatics, law, economics, and medicine.

NCVHS Products

Recent Recommendations, Reports and Presentations

Recommendations on supporting community data engagement by increasing alignment... 06/28/2016

Coordination of Benefits, HPID, & ICD-10 Delay... 08/23/2014

Health Care Claim Attachments... 08/23/2014

UDI in Administrative Transactions... 08/23/2014

view more >

Featured Items

Supporting Community Data Engagement – An NCVHS Roundtable... 10/28/2014

Joint Roundtable on Health Data Needs for Community Driven Change Summary Report... 06/02/2013

A Stewardship Framework for the Use of Community Health Data... 12/06/2012

The Community as a Learning System for Health: Using Local Data to Improve Local... 12/13/2011

view more >

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Hyattsville, MD 20782-2002

HHS.gov www.hhs.gov/ HealthIT.gov www.healthit.gov CDC www.cdc.gov CMS.gov Centers for Medicare & Medicaid Services www.cms.gov ASPe.hhs.gov/ds/ncvhs/

Walter G. Suarez, MD, MPH

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

Health is a Community Affair

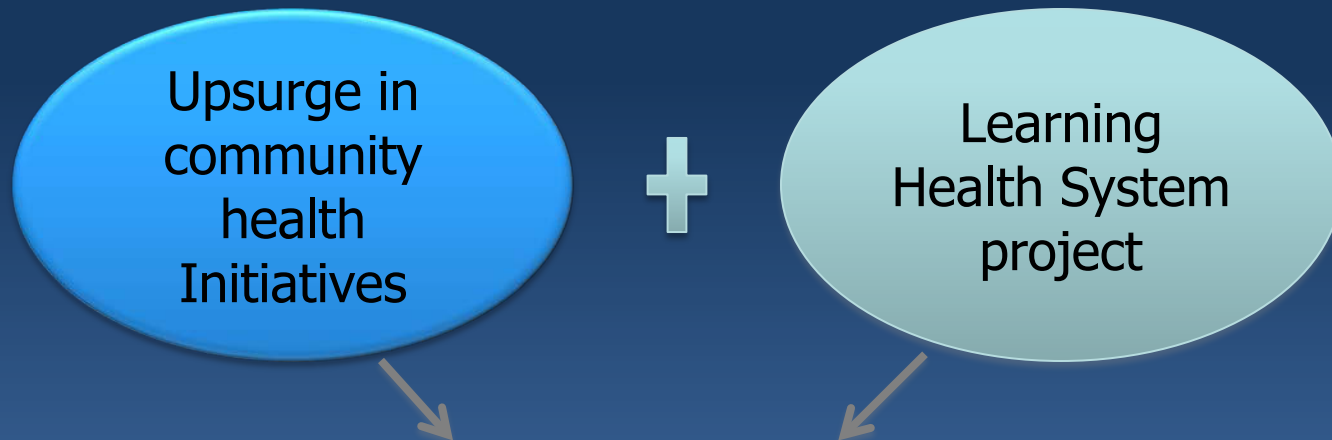
"Getting data into the hands of communities and ensuring they have tools and capacities to use them could move the nation toward realizing the public benefits of the informatics revolution."



*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



How communities can become learning systems for health and what resources exist and are needed to help them?



Published, November 2011
Joint Project of the
Population Health and
Privacy, Confidentiality and
Security Subcommittees

The Community as a Learning System: Using Local Data To Improve Local Health

A Report of the
National Committee on Vital Health Statistics



U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES

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

Joint Roundtable on Health Data Needs for Community-Driven Change

A Summary Report of the
National Committee on Vital Health Statistics



U.S. Department of Health
and Human Services

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.

Letter to the Secretary: an excerpt

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



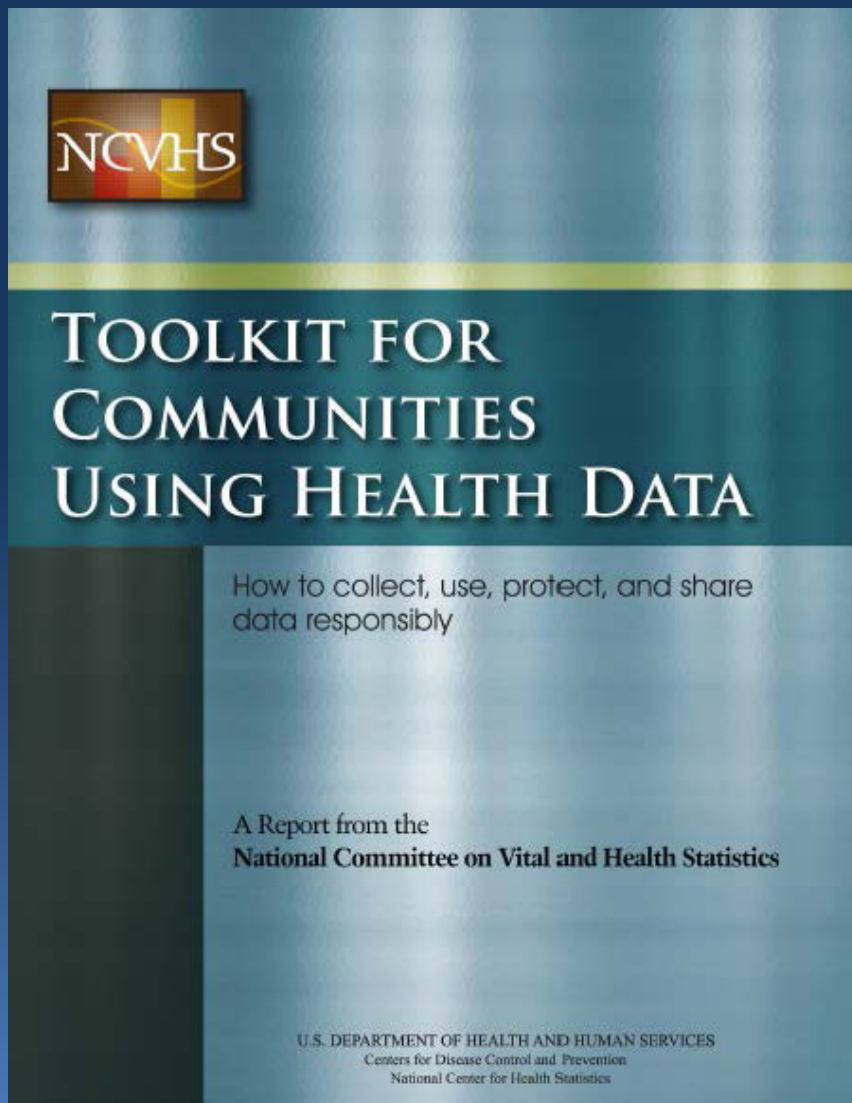
Letter to the Secretary: Recommendations (cont.)

- 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?

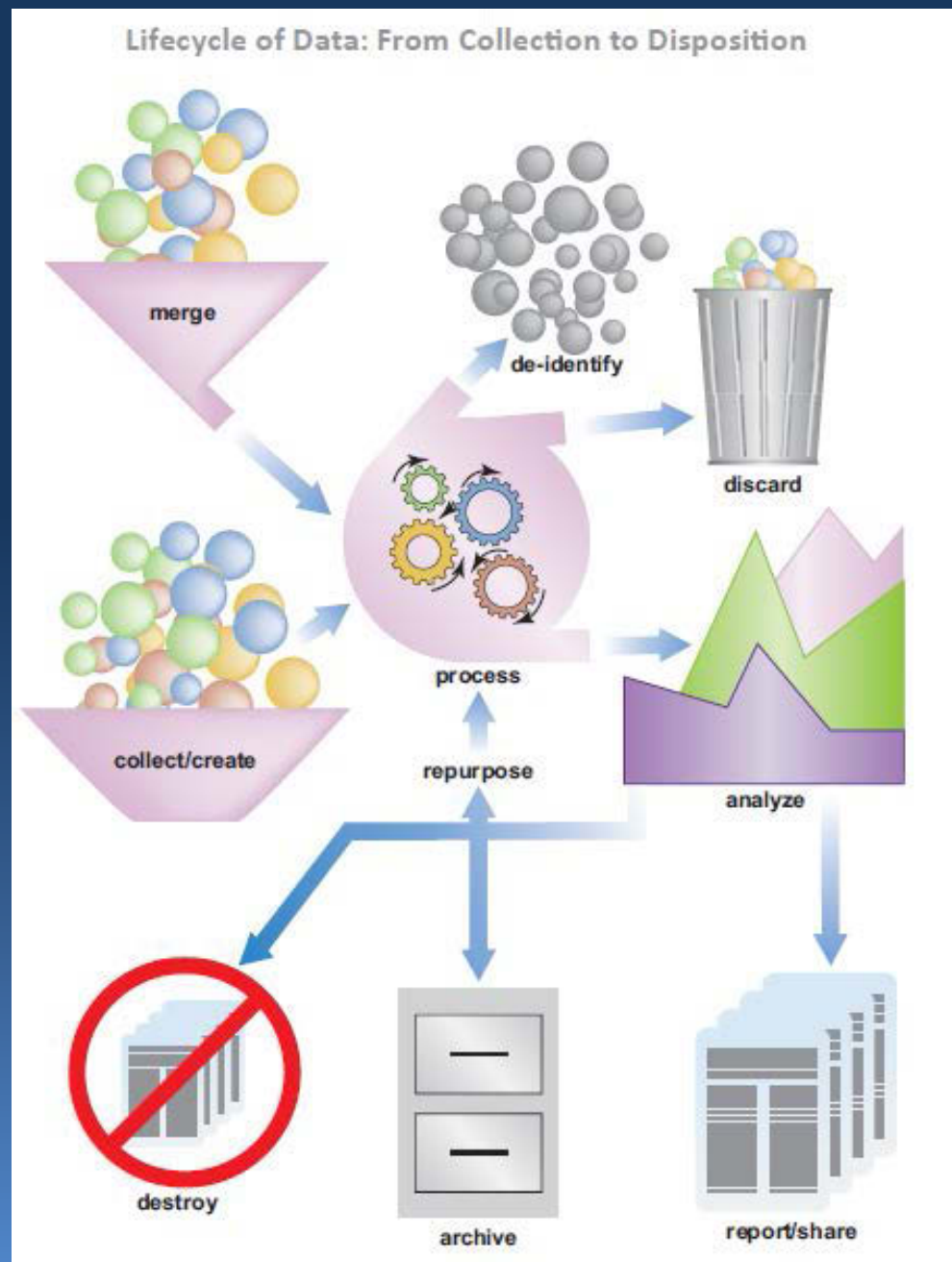
- The responsibility, guided by principles and practices, to ensure the knowledgeable and appropriate use of data

Why a Toolkit and Why Now?

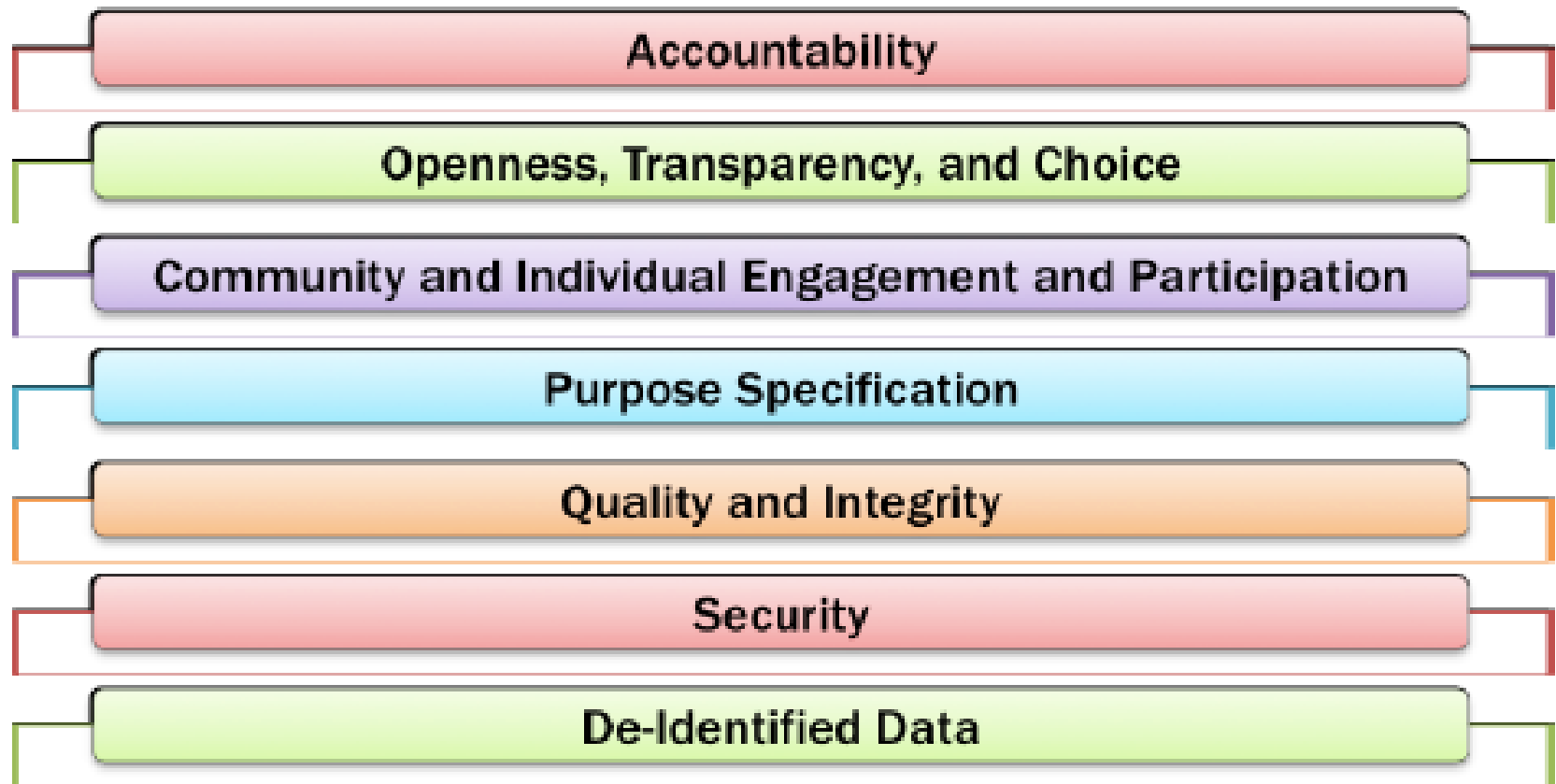
- Communities asked for practical guidance
- Illustrates principles in NCVHS's letter to the Secretary on *Stewardship Framework for the Use of Community Health Data* (Dec 5, 2012)
- *Stewardship Framework* principles and their application defined, explained and illustrated.
- Applicable laws and regulations 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



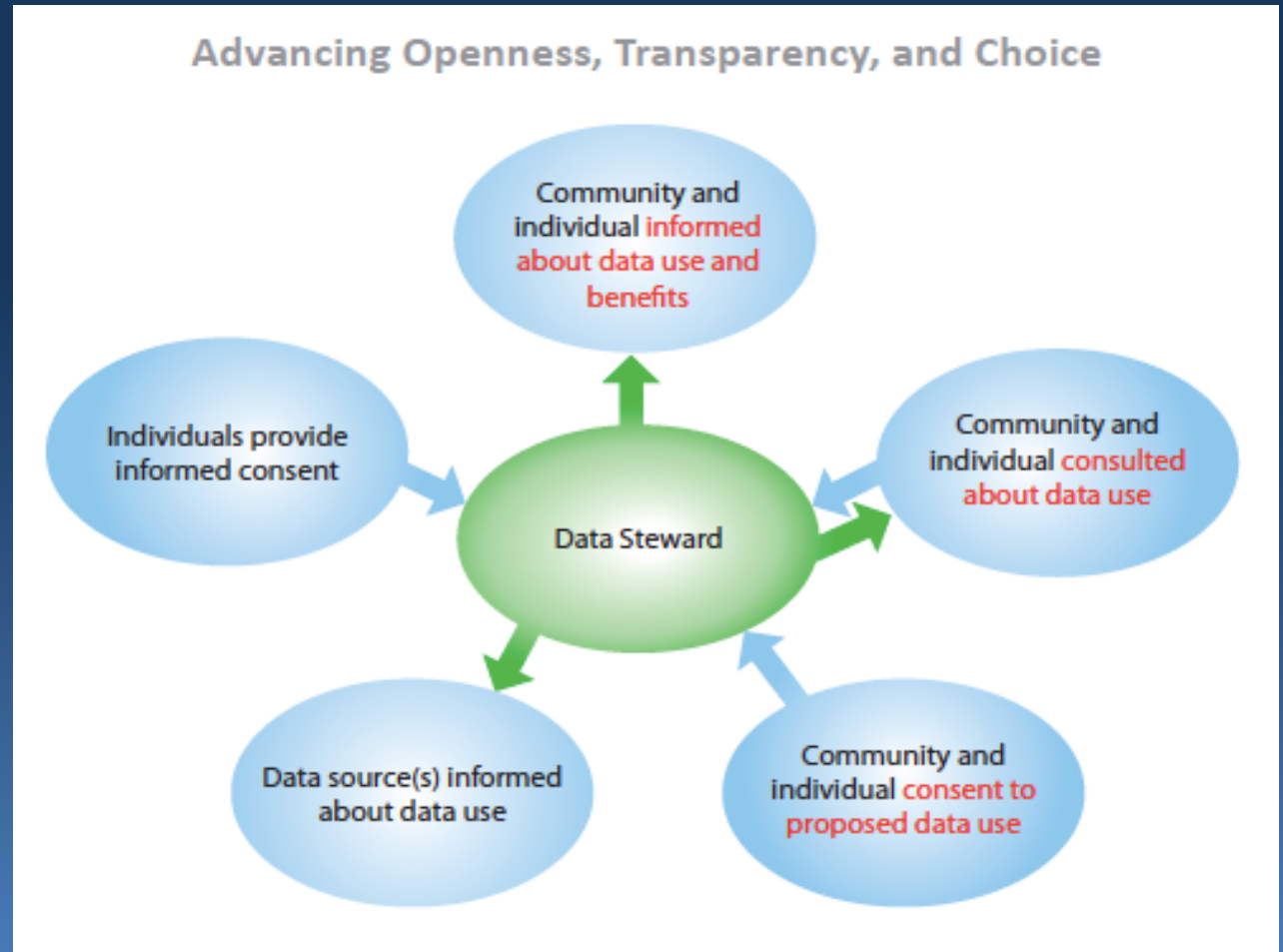
Accountability

- 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

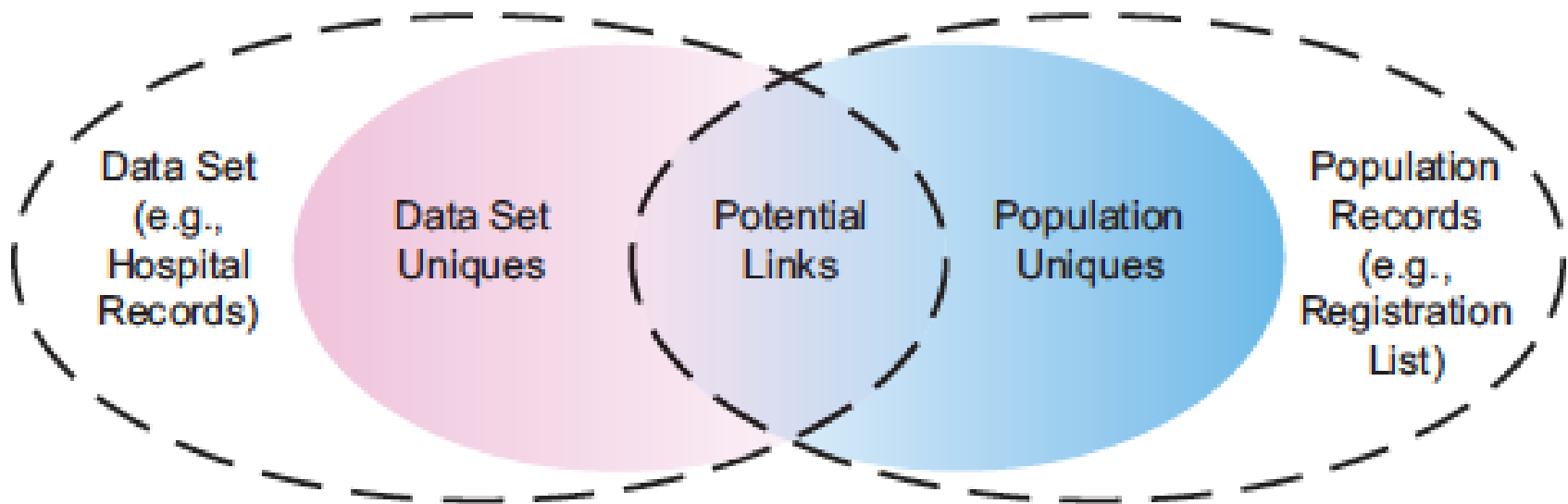
Administrative

- ✓ 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

Looking for Unique “Fingerprints” in a Database⁷



Certain combinations of values may be so rare that they create a “fingerprint” pointing to only one person

Vickie M. Mays, PhD, MSPH

Guidance on Increasing Usability and Accessibility of Federal Health Data

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?

Kenyon Crowley, MBA, MS

Improving Access and Use of Federal Health Data

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!

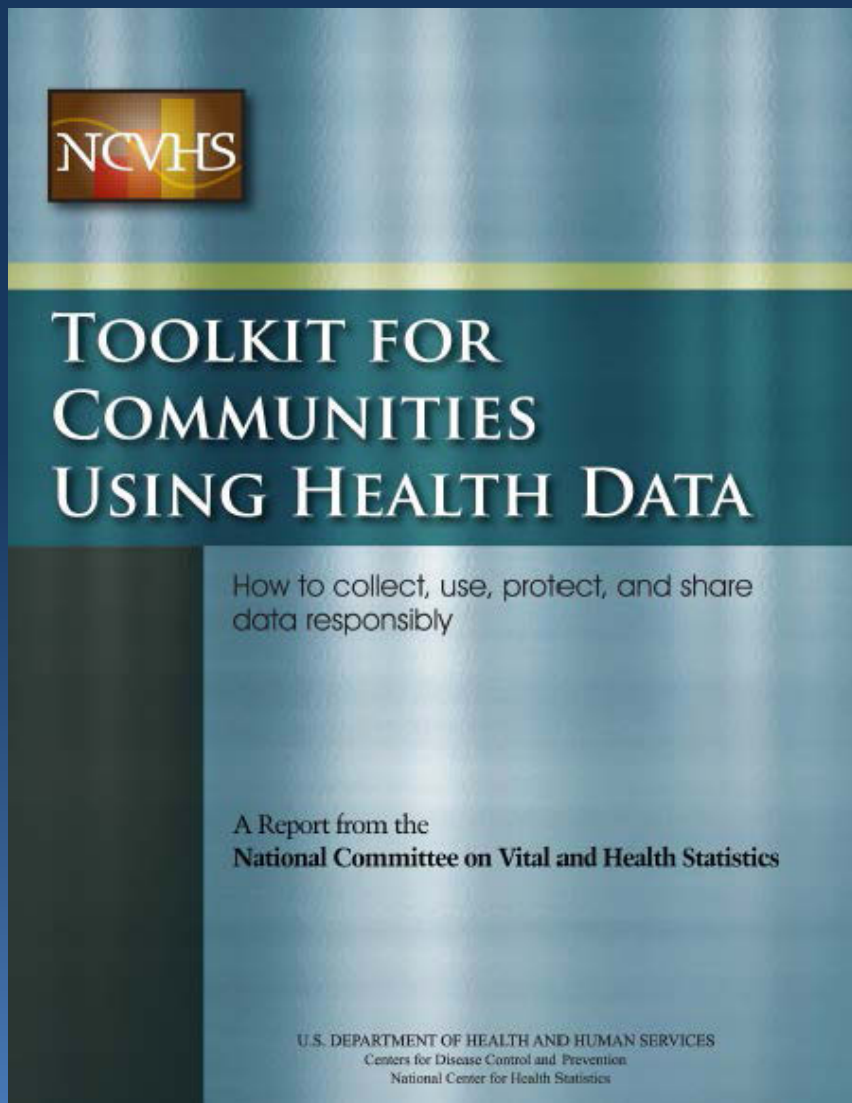
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Executive Secretary
(Acting), NCVHS
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Key Reports:

- **The Community as a Learning Health System: Using Local Data to Improve Local Health -**
<http://www.ncvhs.hhs.gov/wp-content/uploads/2014/05/111213chip.pdf>
- **Joint Roundtable on Health Data Needs for Community-Driven Change - <http://www.ncvhs.hhs.gov/130430sm.pdf>**
- **Toolkit for Communities Using Health Data: How to Collect, Use, Protect and Share Data Responsibly -**
<http://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/Toolkit-for-Communities.pdf>



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