The National Committee on Vital and Health Statistics

The Public Advisory Body to the Secretary of Health and Human Services

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

National Conference on Health Statistics

August 7, 2012

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U.S. Department of Health and Human Services

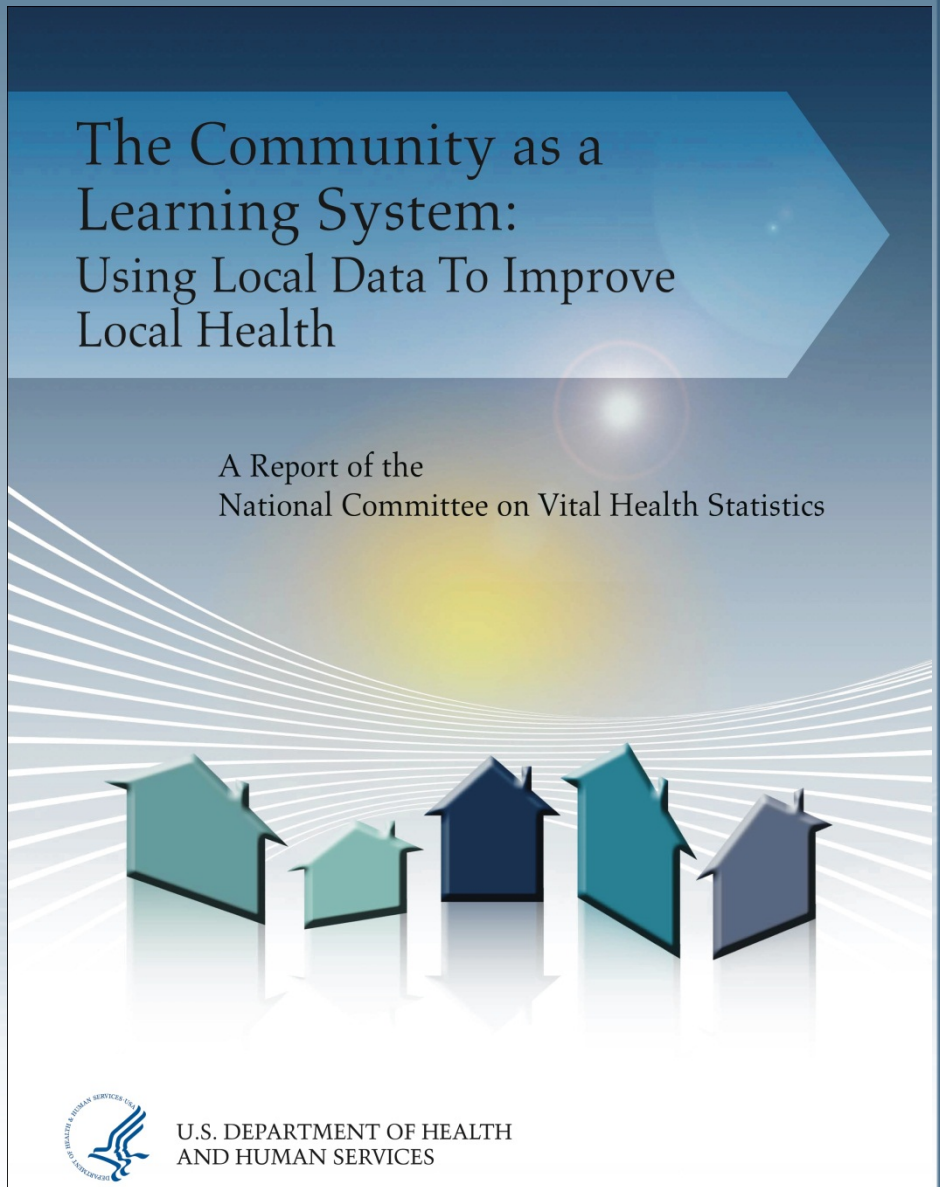
Today's Goals

1. To engage you in improving community health through the use of local data.
2. Update you on the work of the NCVHS
3. Solicit your involvement in the Committee's deliberations.

Presentation Outline

- NCVHS Background
- Overview of Community as a Learning Health System
- Learning from Local Solutions
- Needs, Issues, Gaps
- Trust and Privacy Framework
- Envisioning a Federal Role and Future Directions

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



The National Committee on Vital and Health Statistics - Mission

- The statutory public advisory body to the Secretary of Health and Human Services in the areas of health data, statistics and health information policy
- Provides advice and assistance to the Department
- Serves as a forum for interaction with interested private and public sector groups on a variety of key health data issues.

NCVHS Milestones

1949	Established as federal advisory committee
1974	Public Health Services Act gave NCVHS official status as a 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

NCVHS Configuration

- 18 members appointed for four year terms
- Drawn from fields including medicine, law, public health, economics, privacy, security, informatics, health plans, consumers
- Through hearings and open deliberation, develop practical, timely, thoughtful recommendations to the Secretary of HHS

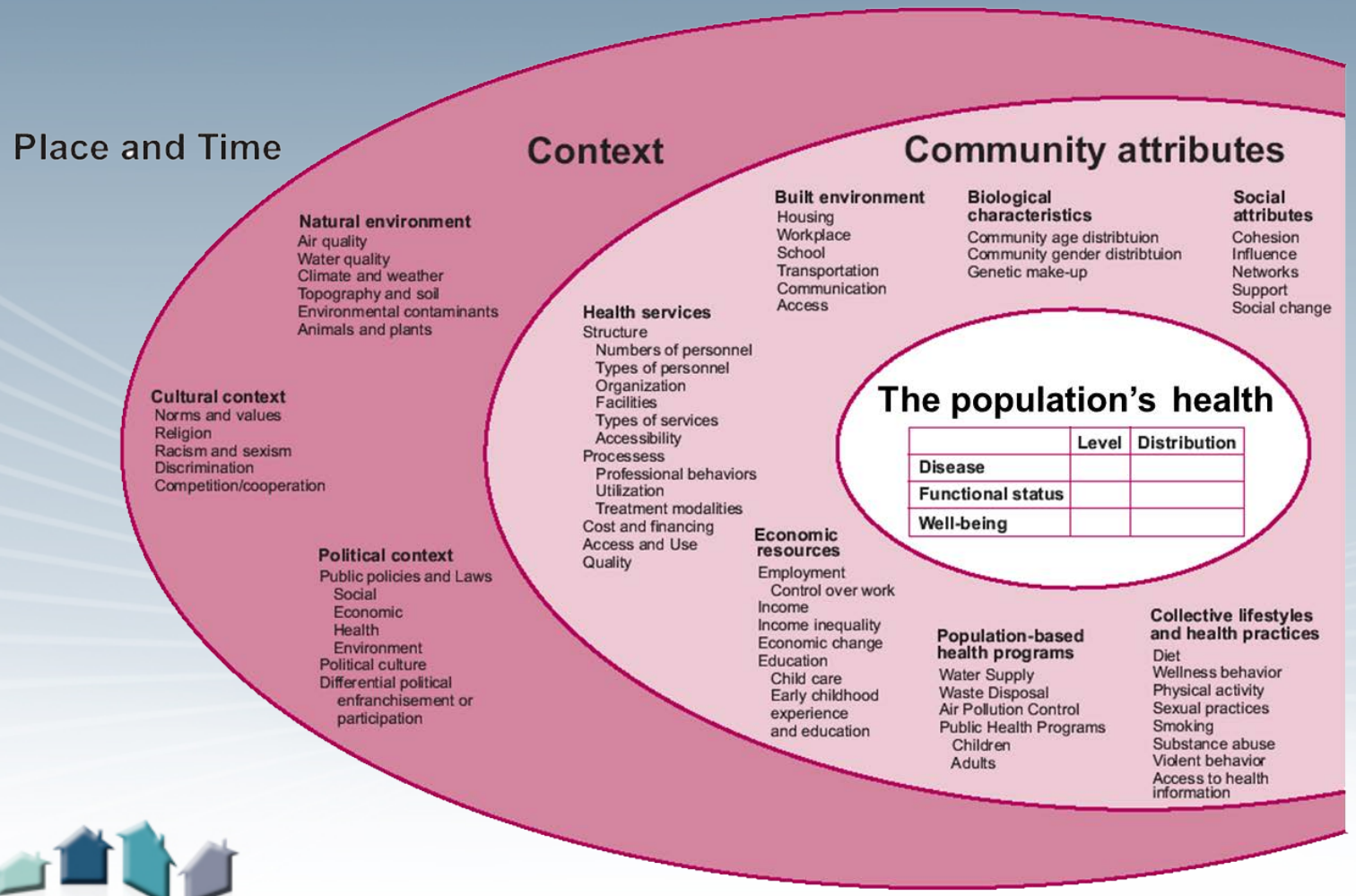
NCVHS Subcommittees

	Focus
Standards	Health data standards as required under HIPAA, MMA, and ACA
Quality	Health data for clinical uses, quality improvement, and informed consumers
Population Health	Population-based data and data about specific vulnerable groups
Privacy, Confidentiality and Security	Emerging issues in information privacy, confidentiality and security and data stewardship

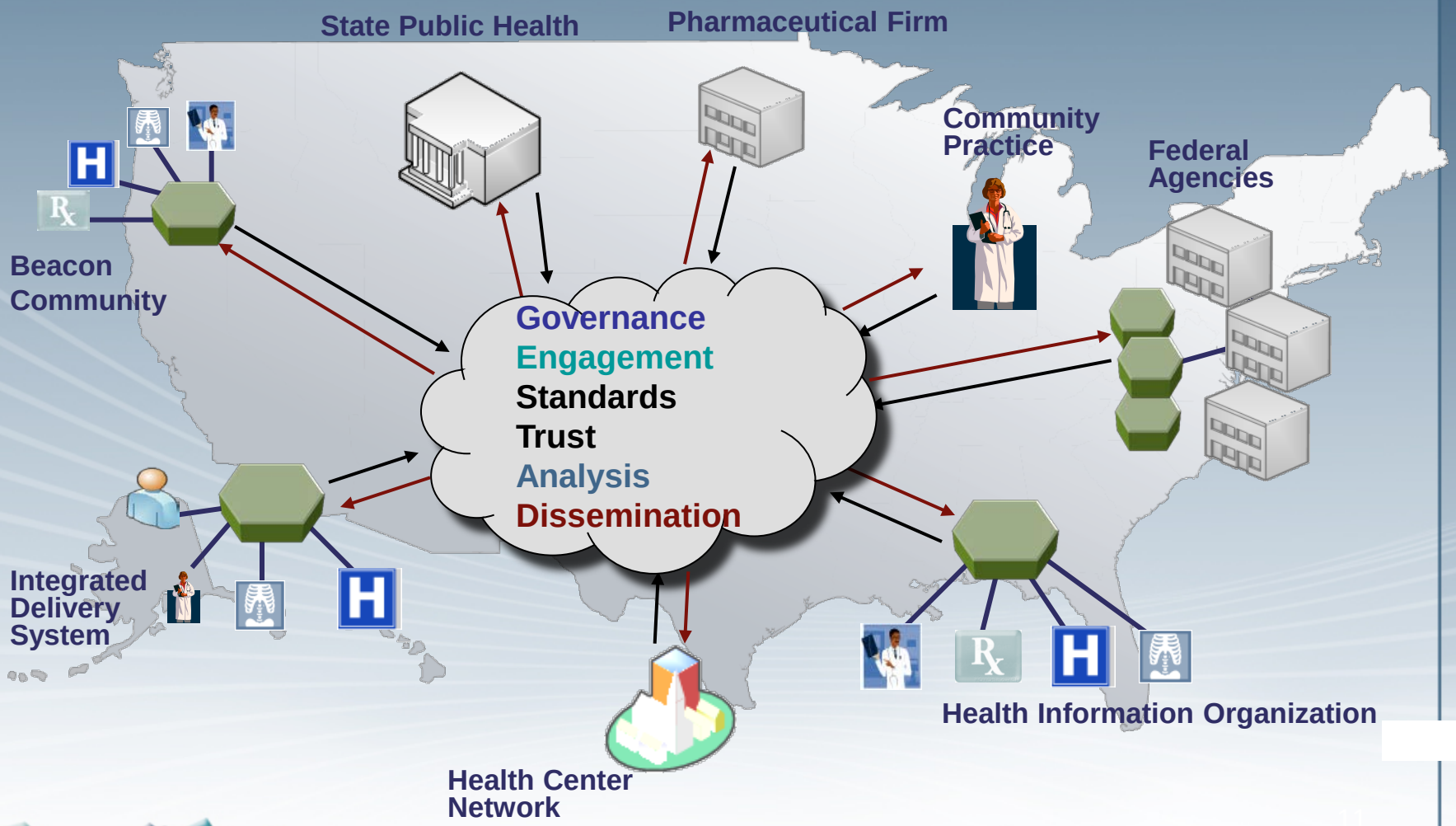
NCVHS Notable Contributions

- Visioning Documents (2002)
  - 21st Century Vision for Health Statistics report
    - Emphasized role of all factors influencing health
  - National Health Information Infrastructure:
    - Led to creation of Office of the National Coordinator for Health Information Technology
- Administrative Simplification
  - Decade of oversight of adoption and implementation of standards for HIPAA and ACA administrative simplification provisions

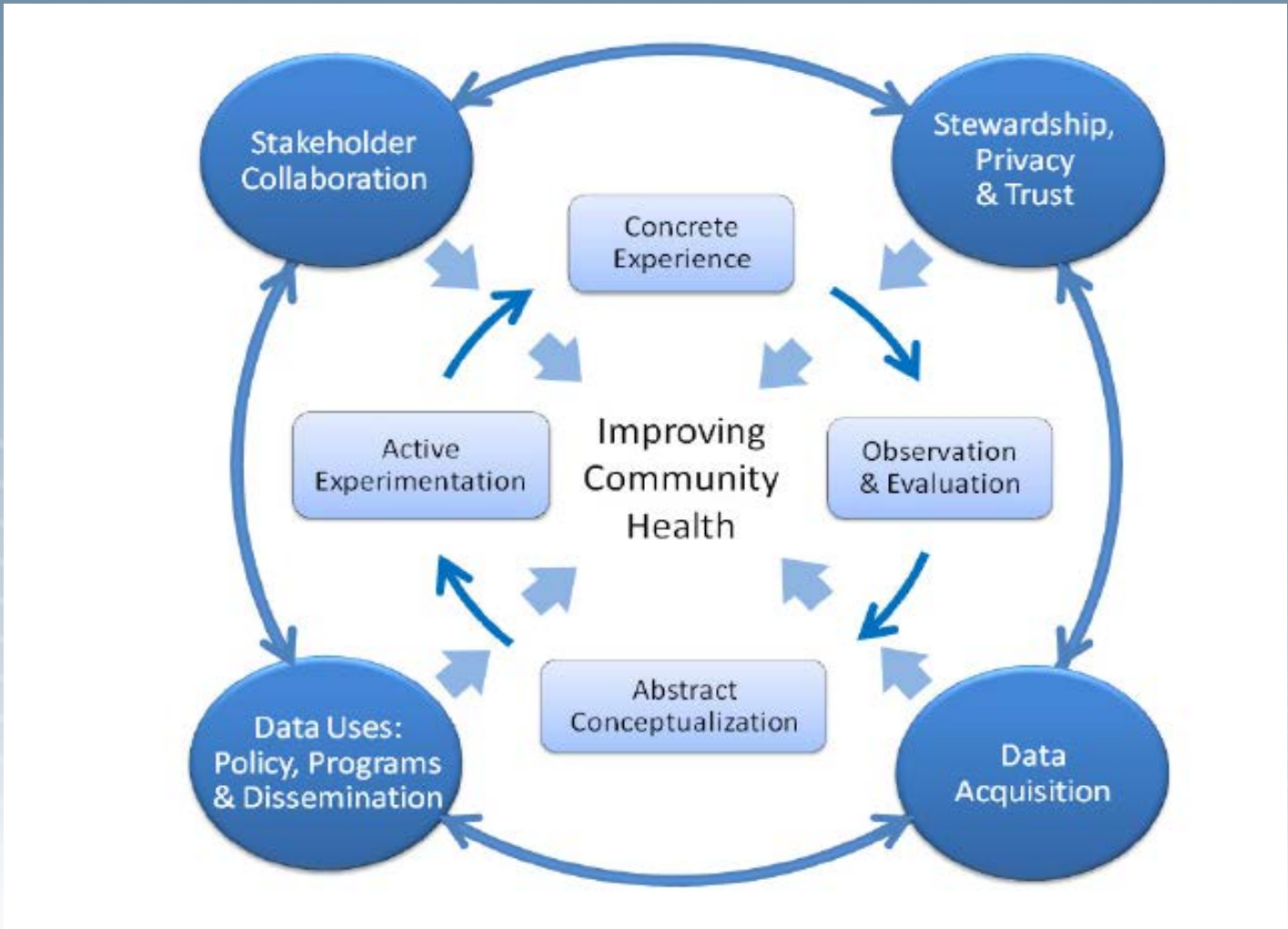
Shaping a Health Statistics Vision for the 21st Century (2002)



A Learning Health System



Key Elements of a Learning Health System



Source: Kolb. D. A. and Fry, R. (1975) "Toward an applied theory of experiential learning" in C. Cooper (ed.) *Theories of Group Process, London: John Wiley*

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

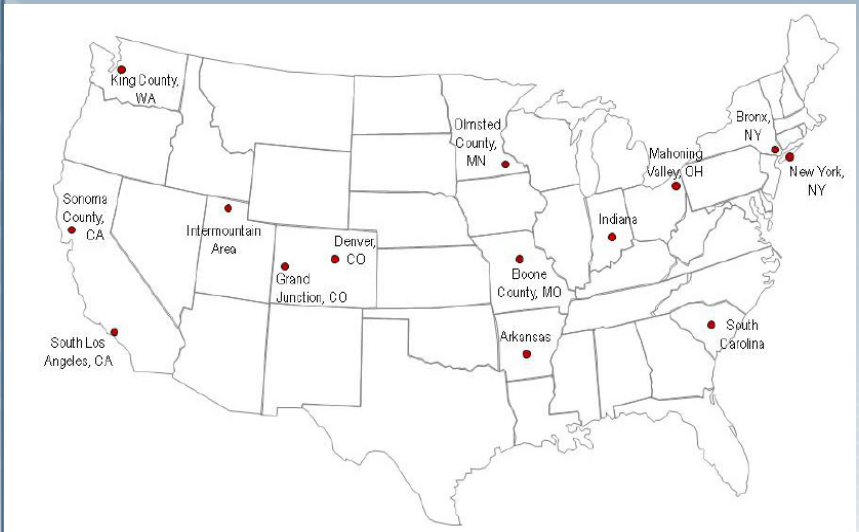
How communities can become learning systems for health and what resources exist and are needed to help them?

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

14 Leading edge Learning Communities



1. **Boone County,** MO – *Public Health*
2. **Bronx, NY** – *Care transitions*
3. **Denver, CO** – *cardiovascular health, childhood obesity*
4. **Grand Junction, CO** – *population health*
5. **Indiana and HIE** – *population health*
6. **King county, WA** – *data democratization*
7. **Mahoning Valley, OH** – *children's health insurance coverage*
8. **New York City**- BMI screening for children
9. **Olmsted County, MN** – childhood asthma
10. **Sonoma County, CA** – health information for citizens
11. **Columbia, SC** – data to improve childcare
12. **South Los Angeles, CA** – land use policies and health disparities
13. **State of Arkansas** – childhood obesity
14. **Utah** – consumer education about health data use

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GO
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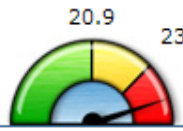
County | Time Period | HP 2020 Target



Red > 23.0
Green <= 20.9
In-between = Yellow
Unit: deaths/100,000 females
View the Legend

Age-Adjusted Death Rate due to Breast Cancer

Value:	26.2 deaths/100,000 females
Measurement Period:	2007-2009
Location:	County : Sonoma
Comparison:	CA Counties
Categories:	Health / Cancer Health / Mortality Data Health / Women's Health

What is this Indicator?
This indicator shows the age-adjusted death rate per 100,000 females due to breast cancer.

Why this is important: Breast cancer is the most common type of cancer among women in the U.S. other than skin cancer. Breast cancer forms in tissues of the breast, usually the ducts (tubes that carry milk to the nipple) and lobules (glands that make milk). In the United States in 2009, it is estimated that there will be 192,370 new cases and 40,170 deaths from breast cancer.

The Healthy People 2020 national health target is to reduce the breast cancer death rate to 20.6 deaths per 100,000 females.

Technical Note: The distribution is based on data from 57 California counties. The value represents the average annualized rate

RELATED CONTENT

LOCAL 211 RESOURCES CALL 211

- Women's Health Specialists : Women's Health Specialists
- Sutter Health : Women's Health Resource And Breast Care Center
- Sutter Health : Women's Health Resource And Breast Care Center
- Sonoma Valley Community Health Center : Sonoma Valley Community Health Center

More

NEWS

- Benefit of mammograms even greater than thought
- Mammograms may

Identifying priorities and building partnerships and collaboration

- Involving citizens and community groups; generating new partnerships
- The role of local data

"Consensus about local priorities emerges when quantitative data are combined with community members' insights and preferences."

The Community as a Learning System for Health, NCVHS, December 2011, p. 12

Developing data around a broad definition of health

- Leveraging and linking multiple data sources on health and determinants
- Linking clinical and population health data
- Generating local data
- Innovatively displaying and disseminating data: dashboards and more
- Mobilizing for information-driven action and evaluation
- Town-gown partnerships to improve local health

Building Trust

- Educating community members and leaders about data use and benefits
- Involving community members in decisions about data use and more
- Trust-building among organizations and agencies that are data sources
- Governance fosters a sense of ownership and control

"…further efforts and leadership are needed to define a privacy and security framework to guide the innovative uses of local data emerging in communities across the country."

The Community as a Learning System for Health, NCVHS, December 2011, p. 19

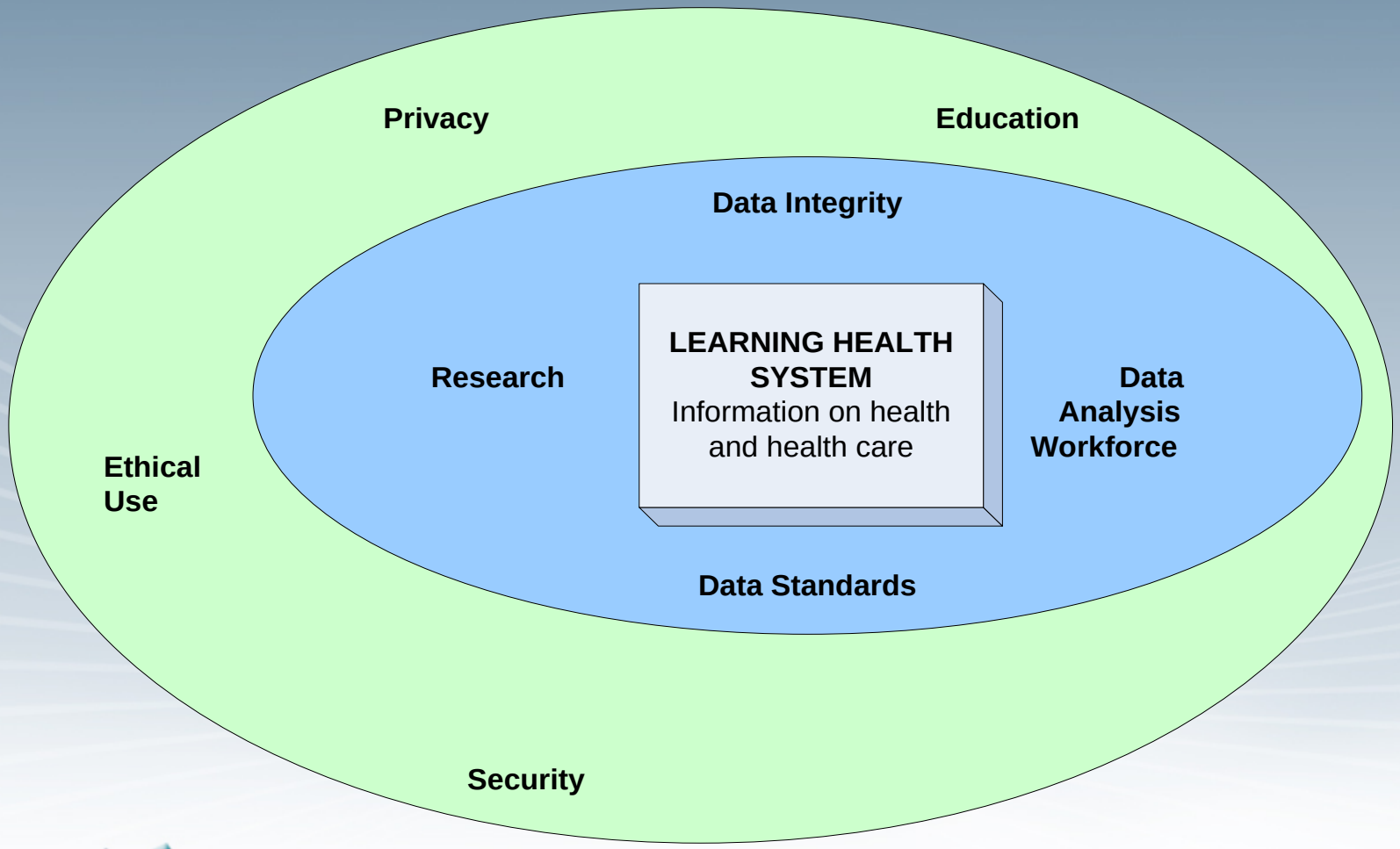
Trust and the Community: Hearings on April 17-18, 2012

- Privacy is not an individual issue only, it's societal and family
- Chain of trust involving the whole process from collaboration through use of data
- Participatory Governance and special obligations of data stewards to the community
- Spectrum of consent

"Trust is our Most Important Resource….and Trustworthy practices require attention to relationships and accountability."

Kelly Edwards, PhD, Department of Bioethics and Humanities University of Washington School of Medicine

HEALTH DATA STEWARDSHIP



Health Data Stewardship: What, Why, Who, How-- An NCVHS Primer (2009)

Building a Stewardship Framework: Steps so Far

1. Surveyed major existing frameworks
2. Identified gaps in these frameworks as they apply to community data uses—areas that are simply not addressed in existing frameworks (although they are present in privacy/trust discussions)
3. Planned a letter that will present issues raised by these gaps and recommendations for study

Identified Gap # 1

- De-identified Data
  - Diminishing distinction between identifiable and de-identified data
  - What mechanisms are needed to follow de-identified data and ensure that any restrictions on re-identification are followed?

Identified Gap # 2

- Enhancing data sets
  - Mash-ups may provide new and unanticipated information, new analytic possibilities, new possibilities for identification
  - What should community data stewards do with respect to mash-up issues?

Identified Gap # 3

- Community consultation
  - When is community consultation appropriate, required?
  - What forms should it take?
  - How should members of the community be identified and involved?
  - How do answers to these questions differ with different types of communities?

Identified Gap # 4

- Communication with communities
  - What information about results of data use should be returned to communities?
  - What responsibilities do data stewards have about returning results to communities as a whole or to individuals within them?
  - Should data stewards withhold information (temporarily or for longer) if communities object to its dissemination (for reasons such as potential stigmatization)?

Identified Gap # 5

- Community impact/burden
  - How should the burdens that data collection may impose on communities be handled?
  - What problems are raised when particular communities are frequent sources of data for inquiry?

Identified Gap # 6

- Non-discrimination
  - Some information about community health has the possibility of putting communities at risk for discrimination—e.g. red-lining in housing markets
  - How should communities be protected against these risks?

Identified Gap # 7

Structuring data repositories

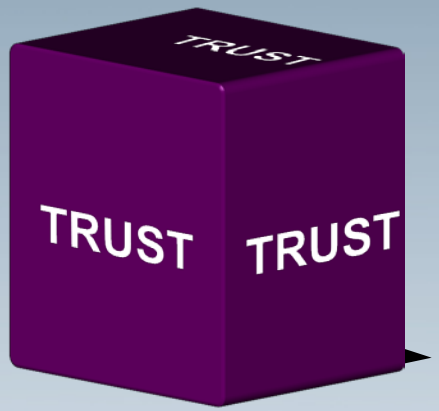
- When should centralized repositories be a model for community data use?
- When should distributed query mechanisms be employed instead, or other mechanisms that leave data where it was originally gathered?

Success Factors in Community Learning Systems for Health

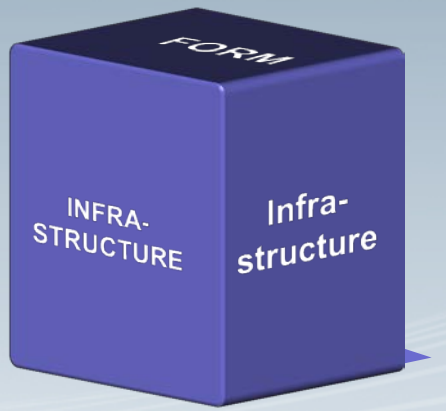
1. A galvanizing health concern.
2. A comprehensive understanding of health and community health.
3. Collaborative culture; social capital.
4. Trust and community engagement.
5. Access to data on local health and its determinants, plus analytic capacities.
6. Data display and dissemination capacities.
7. Functioning coalitions, community engagement, agreement on priorities.
8. Organizational and technical support.
9. Political and financial support.
10. Processes and systems to translate information and priorities into action, evaluate results, and modify as needed.

Needed: An Infrastructure for support, shared learning and economies of scale

Access + analytics + skills to make data usable and useful.



Stewardship + privacy protection + engagement + governance = Trust



Support, facilitate shared learning, and create economies of scale

Needed: An infrastructure for support, shared learning, and economies of scale.

- Privacy and security framework
- Standardized set of community health indicators
- Training, technical assistance and easy to use tools for data management, display and analysis
- Stronger local financial and human resources
- Support for public health departments to take advantage of Meaningful Use criteria
- Help with translating local knowledge into action
- Mechanisms for sharing learning beyond the community

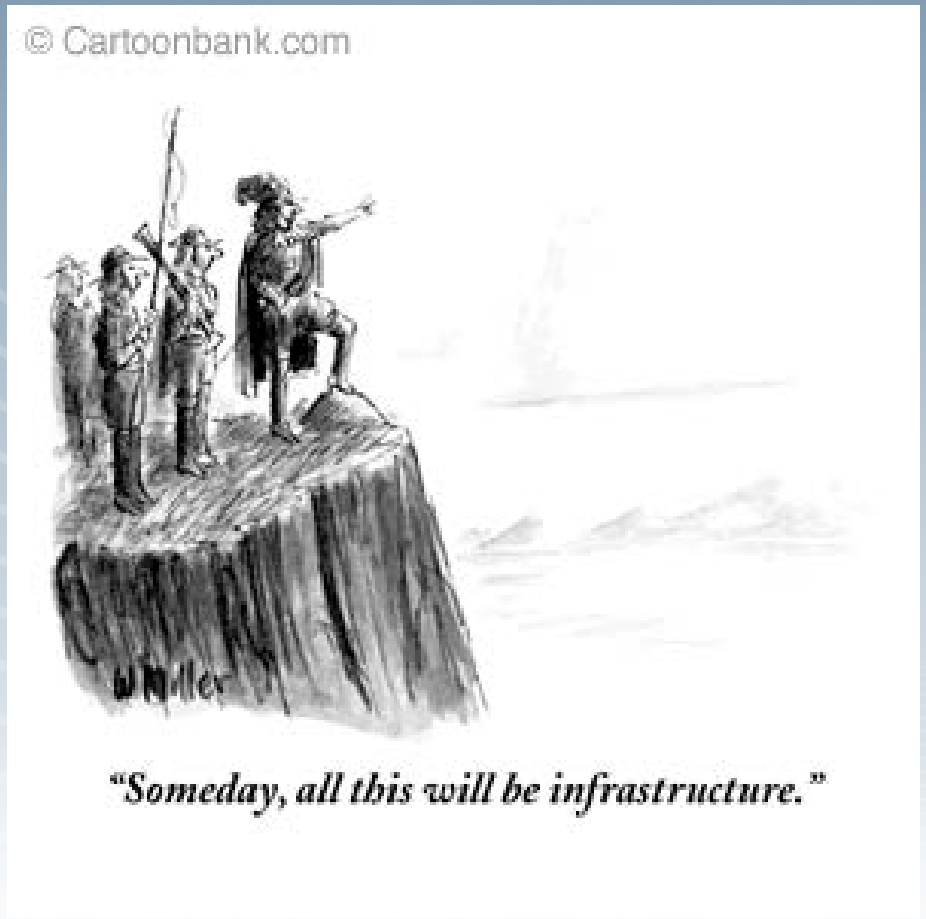
Examples of Enabling Federal Assists

- Better bridges between clinical and public health data systems
- Standardized community health, health status, environmental and resource use indicators
- Federal and state web-based data query systems for small area data, easy analytics and visualization
- Technical assistance perhaps through existing HIT initiatives such as regional extension centers
- Longer funding periods, and transitional support for institutionalization of promising new policies and program

Conclusions and Future Directions

- Need for community-oriented infrastructure that incorporates all the elements outlined in the report
  - Governance
  - Trust and Data Stewardship
  - Data issues
  - Trained resources
  - Tools and analytics
- Opportunities to pursue areas where further research needed
  - Privacy and trust framework
  - Principles for data aggregation
  - Guidelines for local knowledge management and standardization
  - Models and best practices

Questions



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The Community as a Learning System Report: http://www.ncvhs.hhs.gov/111213chip.pdf

Please visit our Homepage for Meeting Information: http://www.ncvhs.hhs.gov/